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Self-Care Behaviors of Women Living with Heart Failure: A Mixed Methods Study

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Susan Bartos, PhD
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Self-care is paramount to the successful management of heart failure. Although recent trends in heart failure have shown a decline in hospitalizations and emergency room visits, observational unit admissions related to heart failure exacerbations continue to rise (Albert, 2016). While nearly half (47%) of the heart failure population is female, women are historically under-represented in heart failure research that guides best practice recommendations (Pressler, 2016). Therefore, the primary aim of this mixed methods study was to identify differences in women who demonstrate an adequate heart failure self-care maintenance (score $\geq$70) behaviors as compared to women who score inadequately (score $\leq$ 69) as measured by the Self-Care of Heart Failure Index (SCHFI) version 6.2. Quantitative data revealed a significant, parabolic relationship between heart failure self-care maintenance and self-care confidence scores. Qualitative analysis suggested that assuming an active or passive role in heart failure self-care plays an important role in women's heart failure self-care maintenance. Mixed methods analysis revealed that high heart failure self-care confidence levels may not reflect an adequate level of heart failure self-care maintenance behaviors. Further research is required to expand on the factors that were found to both facilitate and impede heart failure self-care and to continue to improve health outcomes for women with heart failure.

Self-Care Behaviors of Women Living with Heart Failure:

A Mixed Methods Study

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A Mixed Methods Study

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Table of Contents

Chapter 1: Introduction 1

Introduction to the Research Problem 1

Background to the Research Problem 3

Theoretical Framework 3

Statement of the Problem 7

Purpose Statement 8

Research Questions 8

Worldview: Pragmatism 9

Significance to Nursing Science 10

Novelty of the Study Design 10

Definition of Essential Concepts 11

Summary 12

Chapter 2: Review of the Literature 14

Introduction 14

Factors Influencing Self-Care 14

Quantitative Studies Using the SCHFI 15

International Studies Using the SCHFI 16

Domestic Studies using the SCHFI 18

Quantitative Studies Specific to Heart Failure Self-Care 21

Heart failure and Self-Care Confidence 21

Qualitative Studies of Heart Failure Self-Care 23

Mixed Methods Studies of Heart Failure Self-Care 27

Contributions to Nursing Science 30

Summary 30

Chapter 3: Methods 32

Introduction 32

Design 33

Inclusion Criteria 35

Setting 35

Sample 36

Participant Recruitment 36

Ethical Considerations 37

Study Procedures for Quantitative and Qualitative Strands 37

Quantitative Strand Sampling 38

Instrumentation 39

Qualitative Strand Sampling 41

Procedure for Quantitative Data Collection 41

Procedure for Qualitative Data Collection 42

Procedure for Quantitative Data Analysis 42

Procedure for Qualitative Data Analysis 43

Procedure for Integrating the Data (Mixed Methods Strand) 43

Threats to Qualitative Internal Validity 43

Threats to Qualitative External Validity 44

Threats to Integrity 44

Data Management 45

Summary 46

Chapter 4: Results 47

Introduction 47

Data Collection 47

Quantitative Results 48

Data Analysis 48

Demographic Profile 49

Power Analysis 51

Research Question One Results 52

Research Question Two Results 53

Qualitative Results 56

Research Question Three Results 58

Research Question Four Results 40

Mixed Methods Results 73

Research Question Five Results 73

Summary 77

Chapter 5: Discussion 78

Introduction 78

Summary of Study 78

Discussion of Findings 79

Quantitative 79

Qualitative 82

Mixed Methods 85

Evaluation of Theoretical Framework 85

Implications for Nursing Education 86

Implications for Nursing Practice 88

Implications for Nursing Research 88

Implications for Nursing Policy 89

Strengths of the Study 90

Limitations of the Study 90

Conclusion 91

References 92

Appendices

Appendix 1 – RN script for patient recruitment 103

Appendix 2 – Self-Care of Heart Failure Index 105

Appendix 3 – Demographics Questionnaire 108

Appendix 4 – Table of Contents: Figures and Tables 109

Chapter 1: Introduction

Introduction to the Research Problem

Cardiovascular disease is the leading cause of death worldwide, accounting for approximately one-third of all causes of mortality and claiming more lives than all diagnoses of cancer combined. In the United States, one in every seven individuals succumbs to some form of cardiovascular disease, which includes complications from hypertension, stroke, coronary heart disease and heart failure (American Heart Association [AHA], 2016). Of these individuals affected by heart disease, the AHA estimates that one in every five Americans will develop heart failure. Currently, nearly six million individuals are living with heart failure with 10% of these cases considered to be in the advanced stages heart failure (AHA, 2016).

Characterized as a chronic, progressive syndrome, heart failure occurs when the myocardial muscle is unable to satisfy systemic demands for blood and oxygen (AHA, 2016). A variety of pathophysiological conditions (including ischemic heart disease, hypertension, arrhythmias, cardiomyopathy and various metabolic disorders) have resulted in a diagnosis of heart failure (Nicholson, 2014). The inadequate supply of both blood and oxygen results in an individual experiencing symptoms such as: shortness of breath, chronic cough, fluid accumulation (edema), excessive fatigue, alterations in appetite, increased confusion or cognitive impairment, and alterations in hemodynamics, like rapid heart rate or decreased blood pressure (AHA, 2013). Although there have been major advances in the diagnosis and treatment of heart failure, the syndrome is still associated with poor physiological and psychological outcomes. Approximately half of all people diagnosed with heart failure die within five years of the diagnosis (CDC, 2015).

Once thought of as a disease that primarily affected males, the rising number of females diagnosed with cardiovascular disease, including heart failure, has shifted the spotlight. The

Centers for Disease Control (CDC) estimates that one in every four women will succumb to heart disease (CDC, 2015). Nearly half (47%) of heart failure patients in the United States are female and the lifetime chance of developing heart failure is similar for both males and females (1 in 5). Heart failure affects the health of women differently than men including: a higher mortality rate (57.8% as compared to 42.2%) (Pressler, 2016), older age at the time of diagnosis, higher incidence of diastolic heart failure with preserved ejection fraction (EF), and a more frequent co-morbid diagnosis of depression (Cleveland Clinic, 2016). In some cases, such as individuals who have not suffered a myocardial infarction (MI), the rate of developing heart failure later in life is higher in women than in men (Stein et al., 2013). Heart failure affects an estimated 2.5 million women in the United States and accounts for nearly 50% of all hospital admissions (Pressler, 2016). Despite these statistics, women are frequently underrepresented in large, clinical trials or research studies, accounting for only about a quarter of study participants (Cleveland Clinic, 2016.)

Self-care is at the foundation of heart failure management and is an essential component of chronic disease management. The World Health Organization (WHO) defines self-care as various activities, conducted individually or within a group of people, such as a community, which promote health and wellness or prevent disease (WHO, 1983). An understanding of the role of self-care in heart failure is imperative to the successful treatment and management of the syndrome. Improving self-care practices has been shown to dramatically decrease hospitalization rates as well as overall quality of life (Boyde et al., 2015).

When compared with men, women conduct heart failure self-care in different ways and are affected by varying physiological factors such as etiology of heart failure (systolic vs. diastolic) and other co-morbid conditions such as depression (Thomas & Clark, 2011; Lee et al.,

2009). How well women manage their heart failure and what outcomes they face, are partly determined by their self-care practices. A mixed methods approach of combining qualitative and quantitative research methods to fully understand the phenomena of self-care maintenance among women with heart failure is warranted (Riegel, Dickson, Kuhn, Page & Worrall-Carter, 2010).

Background to the Research Problem

Both physiological and psychological factors influence an individual's self-care. There is an appreciable difference in the roles of these factors between genders among those with heart failure. Moser and Watkins (2008) investigated characteristics such as cognitive/sensory impairment, functional status, co-morbidities, depression, anxiety and social support on the heart failure decision-making process in both genders. More recently, differences in gene expression, specifically those genes responsible for adrenergic and angiotensin signaling and glucose transport were identified in women with heart failure. These biological differences may lead to a possible explanation of the differences in heart failure etiology between genders (Ginghina, Botezatu, Serban, & Jurcut, 2011). While both genders are affected by some common factors (polypharmacy, co-morbid conditions, treatment recommendations, etc.), fatigue and emotional distress seemed to have a greater impact on women. Low health literacy and previous negative experiences with heart failure exacerbations were also shown to have a detrimental effect on the self-care process (Moser & Watkins, 2008).

Theoretical Framework: Heart Failure Self-Care and Naturalistic Decision Making

A Situation-Specific Theory of Heart Failure Self-Care was first introduced in 2008 (Riegel & Dickson, 2008). Situation-specific theories have been gaining popularity in the nursing literature. Theories that are unique to other chronic conditions including: diabetes mellitus (Song, 2010), Hepatitis B (Lee, Fawcett, Yang, & Hann, 2012), and cancer related pain (Im, 2008) have

been developed. The Situation-Specific Theory of Heart Failure Self-Care aims to link clinical practice, research and theory with the goal of guiding both research and interventions specific to the chronic syndrome (Riegel & Dickson, 2008). According to the theory, self-care maintenance and self-care management are the two phases that make up the heart failure self-care process. The whole process of self-care is supported by the notion of self-care confidence, or the level of an individual's self-efficacy throughout the self-care process (Figure 1).

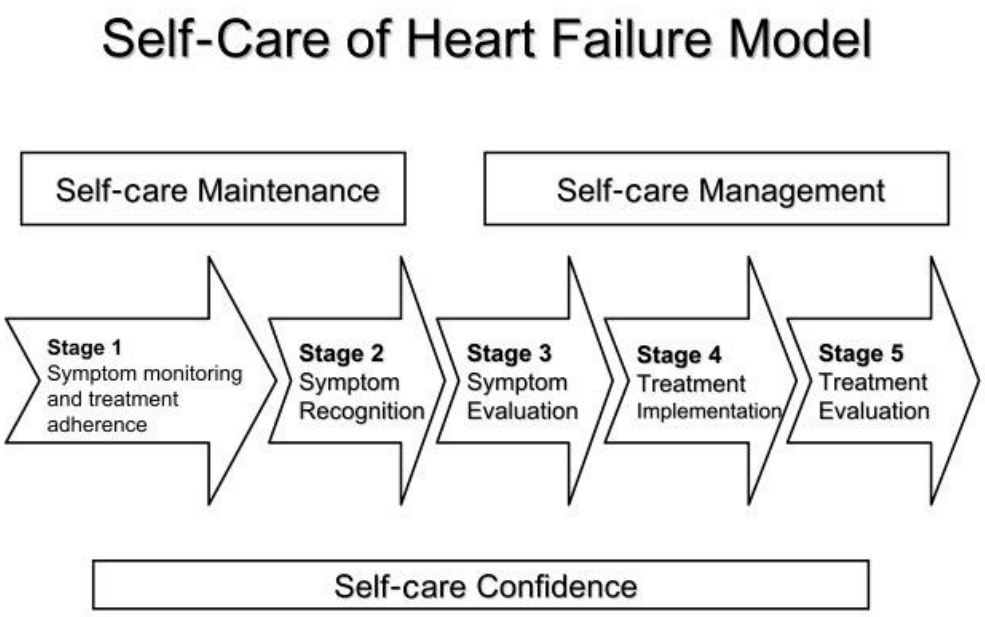


Figure 1: The Situation Specific Heart Failure Self-Care Model (Riegel & Dickson, 2008)

Self-care maintenance refers to the everyday behaviors a patient must undergo to sustain an overall state of physiological well-being. Maintenance behaviors include those that require daily monitoring and quick recognition of exacerbation symptoms. Self-care management is the behavior or self-performed interventions that occur when a patient experiences an exacerbation of the symptoms of heart failure. These behaviors include those that require evaluation of the observed/recognized symptoms and the implementation/evaluation of the prescribed treatments (Riegel, et.al, 2009). Understanding the factors that facilitate and impede a woman's self-care

behaviors and investigating the relationship between self-care maintenance and self-care confidence is crucial in improving self-care practices in women living with heart failure. It is especially important for nursing to fully comprehend both barriers and facilitators to self-care. Nursing is at the forefront of patient education and is often responsible for ensuring patients have adequate resources to conduct heart failure self-care. Evidence-based patient education is essential for optimal chronic disease management (Prasun, 2014).

The Situation-Specific Theory of Heart Failure Self-Care was most recently updated in 2015 to include the process of symptom perception (Riegel, Dickson, & Faulkner, 2015). Symptom perception occurs between the phases of self-care maintenance and self-care management and includes symptom monitoring, recognition, and interpretation. In the newly updated model, self-care maintenance, symptom perception, and self-care management build on each other. The new model is depicted in Figure 2.

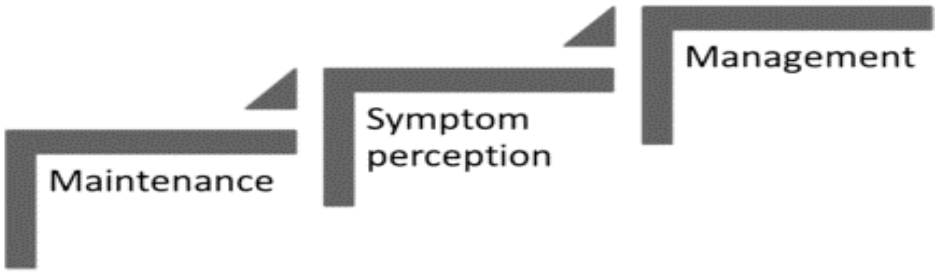


Figure 2: Diagram of the self-care process (Riegel, Dickson, & Faulkner, 2015)

An individual's previous experience with heart failure and heart failure related symptomatology is the foundation of the Situation-Specific Theory of Heart Failure Self-Care (Riegel & Dickson, 2008). Situation-specific theories are unable to be generalized to other diseases. The development of a situation-specific theory includes clear relationships between the theory, previously conducted research, and practice. Situation-specific theories also have a clear,

conceptual scheme and development of a situation-specific theory includes dialogues between colleagues and research participants (Im & Meleis, 1999).

The Situation-Specific Theory of Heart Failure Self-Care is largely based upon the psychological theory of Naturalistic Decision Making (NDM). NDM is the process that an individual undergoes while making a decision. Rather than focusing on the end result, an individual using the NDM process encompasses decision rules and uses available information and situational context to make a final decision (Lipshitz, Klein, Orasanu & Salas, 2001). An individual's previous knowledge and similar experiences influence the NDM process (Riegel & Dickson, 2008). Patients with heart failure that use NDM recall past experiences with heart failure and its related symptoms and use these experiences to determine a care trajectory. Decisions made from NDM are also based on available empirical information, such as a subjective or objective change in condition and the individual's personal values (Riegel, Lee, Dickson, & Carlson, 2009).

The Situation-Specific Theory of Heart Failure Self-Care encompasses the phases of self-care maintenance, symptom perception, and self-care management. Self-care maintenance behaviors are those in which an individual maintains hemodynamic and physiological stability. These behaviors include eating a low sodium diet, exercising, engaging in preventative behaviors, and actively monitoring for signs and symptoms of a worsening condition (Riegel et al., 2009) Self-care maintenance behaviors also include other healthy lifestyle choices such as medication adherence, and symptom monitoring (Dickson et al., 2014). As self-care maintenance is the first step in the self-care of heart failure process, it is critical to improve women's self-care maintenance skills or they will not be able to successfully interpret their symptoms and move into the next phase of self-care, self-management.

The individual shifts to self-care management when symptoms of a heart failure exacerbation occur. Self-care management is a deliberate process and includes the identification, evaluation and treatment of heart failure-related symptoms. These three phases of heart failure self-care are mediated and/or moderated by self-care confidence. Self-care confidence is thought to influence self-care on heart failure related outcomes (Riegel et al., 2009).

Statement of the Problem

Patients with heart failure face a complex treatment regimen. They are expected to monitor their weight, maintain a low sodium diet, exercise, follow strict medication regimens, and make regular clinic visits. Effective self-care, with daily symptom monitoring and knowledgeable decision making about symptoms when they occur, may help patients with heart failure maintain an acceptable level of quality of life and avoid repetitive hospitalizations. (Jyergens, Lee, Reitano, & Riegel, 2013).

How well women manage their heart failure and what outcomes they face, are partly determined by their self-care practices. Because the current U.S. health policy climate is focused on improving health care quality while reducing costs to Medicare and other health insurers, the full understanding of women's heart failure self-care behaviors could effectively improve heart failure care for this population. These connotations hold great potential for significant cost savings and improved health-related outcomes. A call for more mixed methods study in this area of research has been made to fully understand the dynamic variables (Riegel et al., 2010). The nature of a mixed methods study is to approach a question through multiple worldviews or paradigms (Creswell & Plano Clark, 2011). Because this study aimed to explore and identify new factors affecting women with heart failure, a mixed methods design to encompass both quantitative and qualitative data was warranted.

Purpose Statement

This mixed methods study addressed self-care behaviors of women diagnosed with heart failure with a specific focus on the self-care maintenance construct of the situation-specific theory as quantitatively measured. The convergent mixed methods design (Creswell, 2015) involved collecting both quantitative and qualitative data at the same time on patients who met the defined eligibility criteria. The primary aim of this mixed methods study was to identify key differences in women who demonstrated adequate heart failure self-care maintenance behaviors as compared to women who scored inadequately as defined by the Self-Care of Heart Failure Index version 6.2 (SCHFI). Adequate heart failure self-care is defined as a score of 70 or higher on the SCHFI v6.2 (Vellone et al., 2013). The effect of self-care confidence as measured by the SCHFI was evaluated and factors effecting individuals of both adequate and inadequate heart failure self-care were determined and analyzed.

Research Questions

This mixed methods study aimed to answer the following research questions:

Quantitative*:*

1. What is the distribution of self-care maintenance in women with heart failure?
2. Is there a correlation between high and low scores of heart failure self-care maintenance and high and low scores in heart failure self-care confidence?

Qualitative*:*

3. What are the different factors that can be identified which facilitate or impede heart failure self-care behaviors in women scoring adequately and inadequately on the SCHFI?
4. What are the motivating factors that influence heart failure self-care behaviors in women who score adequately and inadequately on the SCHFI?

Mixed Methods*:*

5. In what ways do the interview data that investigate self-care in women with heart failure help to explain the quantitative results about self-care maintenance and the influence of self-care confidence in both those scoring adequately and those scoring inadequately as reported on the SCHFI?

Worldview: Pragmatism

The worldview most often associated with mixed methods research is pragmatism. Pragmatism places importance on the research question, rather than the method of research and emphasizes the necessity of utilizing multiple forms of research to obtain the answer to the research questions (Creswell & Plano Clark, 2011). In pragmatism, both inductive and deductive methods are important and it is the most practical method of arriving at an answer that is best supported by the research evidence (Polit & Beck, 2017). Practicality and application often emerge through studies based around pragmatism (Polifroni & Welch, 1999).

Approaching an issue with a classic worldview that supports strictly quantitative (realist) or strictly qualitative (subjectivist) research may lead the researcher to miss valuable information that mixed methods research would discover. Those adopting a pragmatic worldview while conducting mixed methods research should believe that the goal of the research study is to improve the good of the human race. These researchers are not confined to the worldviews of more traditional thinking and hold the belief that an external reality exists. This can be achieved by utilizing all forms of thinking and recruiting all types of knowledge to solve the proposed problem (Florczak, 2014).

Significance to Nursing Science

This study is significant to nursing science through the following four key reasons. First, self-care maintenance is at the foundation of self-care. Second, although self-care maintenance is recognized as a key component of self-care in heart failure, little is known about the everyday experiences of women's self-care behaviors. Current research suggests that the self-care behaviors of women are likely to be significantly different from the behaviors of men (Riegel et al., 2010; Lee et al., 2009; Stamp, 2014). Though there is conflicting evidence in the literature regarding gender differences in heart failure self-care, the vast majority of studies provide evidence that there are important and significant differences in heart failure self-care between men and women. Third, few studies have focused exclusively on women, or have adequate representation of women, although women comprise about half of all heart failure patients. Finally, self-care maintenance is a crucial pre-requisite for self-care management. A woman's ability to make decisions about which actions to perform based on symptoms, will ultimately affect health outcomes and is dependent upon her skills in daily monitoring.

Novelty of the Study Design

The novelty of this study lies in its focus and design. This is the first study to exclusively focus on heart failure self-care maintenance in women using a convergent mixed methodology. In addition, it is the first study to examine the relationship between self-care maintenance and self-care confidence in women. Three mixed methods studies (Riegel et al., 2007; Riegel et al., 2010; Dickson, Worrall-Carter, Kuhn, & Riegel, 2011) have investigated heart failure self-care with a focus on gender differences. These previous studies have combined self-maintenance and management with small sample sizes and a high proportion of men in the sample **(**Table 1).

Table 1: Summary of Heart Failure Self-Care Mixed Methods Studies

Study	Men	Women
Riegel, Dickson, Goldberg, & Deatrick (2007)	18	11
Riegel, Dickson, Kuhn, Page, & Worrall-Carter, 2010)	19	8
Dickson, Worrall-Carter, Kuhn, Riegel (2011)	65	34

A convergent mixed methods research design (Creswell, 2015) represents an innovative approach in gaining a deeper understanding of what positively or negatively affects a woman's day-to-day heart failure self-care maintenance behaviors.

Definition of Essential Concepts

The following terms and concepts are frequently used throughout this study.

Heart Failure

According to the Heart Failure Society of America (HFSA), there is not one definitive definition of heart failure, largely due to the complex nature of its diagnosis and treatment. The current, working definition of heart failure classifies the diagnosis as a syndrome that results from cardiac muscle dysfunction. This dysfunction can be systolic or diastolic, is characterized by both pulmonary and systemic congestion and leads to symptoms such as fluid retention, shortness of breath, fatigue and inadequate peripheral oxygen delivery (HFSA, 2010)

Self-Care

Self-Care, specifically self-care of cardiovascular disorders such as heart failure, refers to the strict adherence to treatments, appropriate response to symptoms, smoking cessation and dietary modifications (Dickson et al., 2013)

Self-Maintenance

Self-care maintenance includes behaviors to sustain physiological stability such as monitoring of vital signs, measurement of daily weight, appropriate levels of physical activity and monitoring for signs/symptoms of a heart failure exacerbation such as increased peripheral swelling (Barbaranelli, Lee, Vellone, & Riegel, 2014)

Self-Care Confidence

Self-care confidence refers to one's self-efficacy, or the belief in one's self to overcome obstacles in order to perform a specific action. One's self-care confidence may be influenced by a number of factors including previous and similar situational experiences (Riegel, Dickson, Faulkner, 2015). Self-care confidence is largely based on the work of Alfred Bandura (1982) where he described self-efficacy as an individual's ability to complete a task successfully.

Summary

This chapter has provided an introduction and overview of the research problem, including the background and significance to nursing science. Research questions and definitions of essential concepts to further the investigation into the self-care maintenance practices of women with heart failure were also presented.

As the number of women diagnosed with heart failure increases, it is imperative that healthcare professionals understand barriers and facilitators to heart failure self-care. Although recent heart failure self-care research has greatly improved the quality of life for this patient population, knowledge and research gaps continue to exist. Findings from this study will contribute to the deeper understanding of heart failure self-care maintenance behaviors and the development of more effective self-care interventions. New knowledge generated from this study aims to reduce the number of unnecessary re-hospitalizations; thereby, decreasing healthcare costs and improving overall quality of life for this vulnerable population.

An examination of current literature is important in understanding the state of the science regarding heart failure practice recommendations, known factors of heart failure self-care, and previously conducted studies using the SCHFI. Chapter two contains the presentation of quantitative, qualitative and mixed methods studies that have been conducted both internationally and domestically.

Chapter 2: Review of the Literature

Introduction

This chapter includes an extensive review of the literature related to self-care and heart failure. Databases were searched for scholarly, peer-reviewed articles published in English from the years 1990 through March of 2016. Emphasis was placed on the years 2011-2016 to ensure a report of the most up-to-date guidelines and recommendations. The databases used in this review include: CINAHL, PubMed, PsycINFO, Cochrane and Proquest and were explored by using a combination of the key words: heart failure, women, female, gender differences, quantitative, qualitative, mixed methods, and self-care.

Factors Influencing Self-Care

In a 2015 position paper on educating patients with heart failure, the American Association of Heart Failure Nurses (AAHFN) reported that approximately 45% of heart failure patients do not receive the necessary 60 minutes of heart failure education prior to discharge from an acute care facility. Multiple barriers from both the healthcare perspective and the patient perspective were reported including lack of time/resources, lack of interest and low health literacy. Patient barriers to heart failure self-care were also identified as older age, ability to understand discharge education, and managing multiple medical co-morbidities. The AAHFN recommends specifically trained heart failure nurses to provide discharge education that includes information about the disease, prognosis and effective self-care behaviors (Rasmusson, Flattery & Baas, 2015).

Lack of knowledge was found to be a factor in ineffective heart failure self-care in a 2014 integrative review. Misconceptions about heart failure, excessive daytime fatigue, poor social support and impaired cognition were also factors contributing to ineffective self-care (Zavertnik,

2014). The ability for a patient with heart failure to recognize a symptom of worsening heart failure and act on it appropriately was identified as a key element of heart failure self-care (Zavertnik, 2014). This emphasizes the importance of strict adherence to self-care maintenance behaviors and daily symptom monitoring.

Similarly, excessive daytime fatigue and decreased cognitive function were symptoms identified that had a negative effect on the functional status of a patient with heart failure and consequently, heart failure self-care. These two symptoms were classified into clusters in a 2014 cross-sectional study that aimed to identify associations between groups of similar symptoms. Heart failure symptom clusters that were identified included: sickness behavior cluster (anxiety, depression, sleepiness, cognitive decline and fatigue), discomforts of illness (shortness of breath, edema, and pain) and GI disturbances (appetite and hunger). Identifying symptom clusters in the heart failure population allows for healthcare providers to anticipate the behaviors of those who are at highest risk of experiencing decline in everyday functioning and heart failure self-care behaviors (Herr et al., 2015).

Over the past decade, several quantitative studies have used the Self-Care of Heart Failure Index as a measure to evaluate patient's self-care abilities. Numerous quantitative, qualitative, and mixed methods studies have been conducted to examine self-care in heart failure.

Quantitative Studies Using the Self-Care of Heart Failure Index (SCHFI)

The Self-Care of Heart Failure Index (SCHFI) was originally developed and published in the year 2004 (Riegel, Carlson, Moser, Sebern, Hicks, & Roland, 2004). It has since undergone multiple revisions to increase the instrument's validity and reliability and an updated version was published for public use in 2009 (Riegel et al., 2009). Since its publication, it has been used in multiple studies worldwide including Italy (Cocchieri et al., 2015), Brazil (Avila, Riegel,

Pokorski, Camey, Silveira, Rabelo-Silva, 2013), and Taiwan (Tsai, Wang, Lee, Tsai & Chen, 2014.). The SCHFI has been translated into multiple languages including Spanish, Dutch, Portuguese, Japanese, Persian, Slovakian, Lithuanian, Albanian and French (Riegel et al., 2015).

International Studies using the SCHFI

The SCHFI has been used to compare heart failure behaviors, both domestically and internationally. In a study encompassing five continents (Europe, North America, South America, Australia and Asia) and 15 countries, recommended self-care behaviors (medication and dietary adherence, exercise, weight monitoring, and communication with a health care provider) were compared using the SCHFI. The SCHFI was used in Germany, Serbia, United States, Australia, Hong Kong, Thailand, and Taiwan. Within this SCHFI framework, self-care maintenance, symptom perception, and self-care management are conceptualized as key patient behaviors. Embedded within the concept of self-care is the idea of self-care confidence which is influential in self-care decision making and actions taken by patients.

Findings from these international studies indicate that compliance with the recommended heart failure self-care behaviors was widely variable; however, there was a trend towards inadequate heart failure self-care globally. Patients most often had adequate medication adherence with a median value of 7% reported not taking medication as prescribed, and inadequate rates of exercise with a range of 36% (Germany) to 90% (Italian) of patients reporting non-adherence to exercise. Healthcare related behaviors, such as obtaining a yearly flu shot, were also variable with a reported range of 16%-75% receiving the vaccination. Because of the high level of variance of heart failure self-care between countries, a specific and culturally sensitive approach to heart failure self-care is recommended (Jaarsma et al., 2013).

In a sample of Taiwanese individuals with heart failure, admission frequency was found to be the only strong determinant of self-care maintenance behaviors (adjusted R^2 = 13.1%). Self-care maintenance behaviors also had a positive correlation with heart failure knowledge (r = 0.27), length of heart failure diagnosis (r = 0.30), frequency of admission (r = 0.38), and number of co-morbid conditions (r = 0.35). Those individuals with multiple hospital admissions scored higher on the SCHFI and had better heart failure knowledge. Because heart failure knowledge influences self-care maintenance, self-care management, and self-care confidence, it was hypothesized that those with multiple admissions received varying levels and repeated heart failure education. Overall, heart failure self-care maintenance behaviors were inadequate in this population with a mean score on the SCHFI of 47.93 and nearly 92% of the participants scoring less than an adequate score of 70 (Tsai, Wang, Lee, Tsai, & Chen, 2014).

Similar to the Taiwanese findings, researchers discovered a lack of heart failure self-care behaviors in an Italian sample. Using the SCHFI to measure the same constructs of heart failure self-care, Cocchieri and colleagues (2015) report about a quarter (24%) of their sampled population to have adequate heart failure self-care behaviors. In this population, male patients scored lower than females in the three domains of the SCHFI; however, only the self-care management scale was statistically significant (p = 0.03). Similar to the Tsai and colleagues international study (2014), obtaining daily weights, physical activity and dietary restrictions were also problematic in the Italian sample. Male patients, when compared to females, seemed to be at greater risk for poor self-care maintenance behaviors especially with checking for ankle edema ($p < 0.001$) and adhering to sodium restrictions (p = 0.001). Self-care maintenance, management and confidence were overall inadequate, with mean SCHFI scores of 55.26, 53.18, and 54.57, respectively. Although the sample was predominantly male (58%), researchers discovered that

widowed women tended to be more cognitively impaired ($p = 0.007$), a characteristic that places an individual at a higher risk of inadequate self-care (Cocchieri, et.al, 2015).

Domestic Studies using the SCHFI

Level of experience with heart failure symptoms was the focus of a 2010, non-experimental study investigating the differences in self-care maintenance and management behaviors as determined by the SCHFI. Level of experience with heart failure symptoms did seem to a improve patient's ability to conduct self-care; however, did not have a positive effect on self-care confidence. The authors of the study concluded that confidence seems to have a moderating effect on health outcomes and a mediating effect on social supports and self-care. Recommendations to focus long-term heart failure education on treating depressive symptoms and improving quality of life are warranted (Cameron, Worrall-Carter, Page, Stewart, 2010).

The relationship between mild cognitive impairment (MCI) and self-care has been investigated. It has been reported that up to 73% of the heart failure population has some form of (MCI) which can have a negative impact on heart failure self-care behaviors. Older age and a greater number of co-morbid conditions were significant determinants of self-care maintenance. Although the influence of MCI contributed to the overall model of heart failure self-care proposed by this study, it was not an independent correlate with either self-care maintenance or management. It was hypothesized that heart failure patients with MCI are still able to perform their self-care duties, specifically self-care maintenance because of the routine nature of the tasks. It is the self-care management behaviors that may pose a problem as these behaviors require a higher level of thinking, acting, and problem solving (Cameron, Worrall-Carter, Riegel, Lo, & Stewart, 2009).

MCI was again investigated as a predictor for heart failure self-care maintenance, management and confidence in a descriptive, correlational study (Davis, Dennison Himmelfarb, Szanton, Hayat, & Allen, 2015). In this study, a sample of 125 (47% female) individuals who screened positive for MCI using the Montreal Cognitive Assessment had higher scores of heart failure knowledge as measured by the Dutch Heart Failure Knowledge Scale, yet inadequate self-care maintenance behaviors (mean score: 63.57) as measured by the SCHFI. Heart failure knowledge scores averaged 11.24 with adequate scores defined as greater than 10. Across both genders, time of heart failure diagnosis and younger age were not significant predictors of heart failure self-care behaviors, while black race and older age were predictive of lower self-care levels. Higher social support, heart failure specific knowledge and educational level all had a positive impact on heart failure self-care. Overall heart failure self-care scores were low with only 35% of the sample reporting adequate self-care maintenance scores as determined by a score of 70 or greater on the SCHFI. In this sample, gender was not a significant predictor for self-care maintenance; however, male gender tended to be predictive or higher self-care maintenance and self-care confidence (Davis et al., 2015).

A number of co-morbidities have been linked to self-care. In addition to cognitive impairments, many heart failure patients are diagnosed with a multitude of physiological co-morbidities. These include, but are not limited to: diabetes mellitus (DM), chronic obstructive pulmonary disease (COPD), myocardial infarction (MI) and hypertension (Dickson et al., 2013). In a secondary analysis of four mixed methods studies (n = 112, female = 38%), researchers discovered that comorbidity as defined by the Charlson Comorbidity Index influenced self-care maintenance behaviors. There was a significant negative correlation between self-care maintenance and the number of co-morbid conditions reported (r = -.253, p = .03). Patients

reported adhering to multiple dietary recommendations, monitoring symptoms and differentiating symptoms between co-morbid diagnoses to be the most challenging self-care practices. Lack of self-care confidence as defined by the SCHFI was discovered to be a barrier to adequate self-care maintenance behaviors and influenced an individual's choices, energy and stress levels (Dickson et al., 2013).

The recent updates to the Situation-Specific Theory of Heart Failure (Riegel et al., 2015) to include symptom perception were reflected in a 2015 study involving regular symptom monitoring and self-care management behaviors. In a sample of 311 individuals with heart failure (35% female), those who were able to identify and react to heart failure symptoms, and to implement and evaluate a treatment (self-care management), were also those individuals who were most adherent to symptom monitoring (self-care maintenance) behaviors, including monitoring for changes in weight and lower extremity edema. This adherent group of individuals was the minority, accounting for 15% of the total sample. This solidifies the importance for comprehensive education regarding heart failure self-care behaviors as patients cited lack of understanding as to why self-care behaviors need to be performed daily. Because regular symptom monitoring, or self-care maintenance, is a precursor to self-care management practices, it is imperative that healthcare providers stress the importance of early symptom recognition (Lee et al., 2015).

As many patients with a heart failure diagnosis live in the community, a community-based approach was the focus of a 2015 intervention study that was conducted to improve heart failure self-care. Using the SCHFI and a randomized controlled trial design, authors tested the feasibility of a self-care intervention that featured six to eight 60 minute educational sessions that took place at a local senior center that focused on heart failure self-care, knowledge and quality

of life. Implementation of this intervention supported the notion that heart failure patients benefit from continued and outpatient education in a community or group setting. Training healthcare providers to deliver heart failure education to more individualized needs may improve self-care practices of a specific community. Participants in this study were from a variety of nationalities and ethnicities which supports the implementation of community-based interventions for heart failure patients in ethnically diverse settings (Dickson, Melkus, Dorsen, Katz, & Riegel, 2015).

Quantitative Studies Specific to Heart Failure Self-Care

Focusing on the unique needs of women is an important aspect of heart failure self-care. In a cross-sectional, correlational study of 122 patients with heart failure, it was determined that men and women have similar levels of knowledge pertaining to the psychological and physiological effects of heart failure. Although knowledge levels are similar between genders, the authors of this study concluded that gender specific interventions for the modifiable risk factors such as self-care confidence are needed. Higher self-care confidence (modifiable) has been associated with better outcomes in the female population while age (non-modifiable) is not associated with better or worse self-care practices (Heo, Moser, Lennie, Riegel & Chung, 2008).

How self-care confidence determines whether a patient may be classified as an expert or novice in heart failure self-care was the focus of a 2011 cross-sectional descriptive study. Riegel and colleagues (2011) described three typologies in heart failure self-care: novice, expert and inconsistent. Novice heart failure self-care individuals were characterized as having low self-confidence while experts were confident in their self-care abilities. Those who were inconsistent had few limitations in their activity and had high levels of self-confidence. The sample in this study was 35.6% female and used the SCHFI to measure heart failure self-care scores. Maintenance, management and confidence scores were measured to be less than adequate on the

SCHFI. However, understanding how increased confidence supports self-care behaviors is important in shifting the focus to those who may be at risk for inadequate self-care (Riegel et al., 2011). This study evaluated the entire process of heart failure self-care including maintenance and management without focusing on a specific gender or a specific aspect of the heart failure self-care process.

In a 2010 cross-sectional, descriptive study investigating self-care and quality of life, women scored higher on the same instrument (SCHFI) and exhibited higher confidence in their self-care abilities when compared to men with heart failure. Women were also shown to have greater knowledge regarding their prescribed diet, particularly adhering to low-sodium guidelines (Britz, & Dunn, 2010).

In addition to self-care confidence, Cené et.al (2013) found perceived social support to influence self-care maintenance behaviors. In a sample of 150 community-dwelling males and females, perceived social support was found to be high. Overall, self-care maintenance was adequate (52% of participants reported a score >70). Approximately half of the sample was female; however, gender differences were not addressed. Higher perceived support was positively and significantly associated with higher self-care maintenance behaviors, but not self-care management practices.

Social support was also found to have an effect on self-care behaviors in a 2015 cross-sectional, descriptive, correlational study (Graven, Grant, Vance, Pryor, Grubbs & Karioth, 2015). Those individuals with heart failure that reported decreased social support seemed to report more depressive symptoms and lacked adequate heart failure self-care behaviors. The authors hypothesized that worsening heart failure symptoms may have a negative effect on social relationships, thereby, decreasing the amount of social support. This investigation also found that

those patients reporting more severe heart failure symptoms were more at risk for inadequate self-care.

In a 2014 review, Stamp investigated the need for a gender-specific approach to improve heart failure self-care in women. Lack of knowledge and understanding of heart failure regimen, decreased social support, and self-care confidence, difficulty interpreting heart failure symptoms, depression and inexperience with a heart failure exacerbation were identified as barriers to heart failure self-care. Facilitators to self-care included making life changes based on heart failure symptoms, conserving energy and taking rest periods, social support, positive healthcare experiences, high self-care confidence and previous experience with heart failure symptoms. Women were also found to have lower levels of self-care maintenance when compared to men. It was determined that a gender-specific approach to heart failure care is needed, including increasing the knowledge of heart failure treatments and interventions (Stamp, 2014). The conclusions from this article support the notion that women with heart failure require special and tailored interventions; however, these findings do not investigate the specific practices of self-care maintenance behaviors or how the level of a woman's confidence influences these behaviors.

Qualitative Studies of Heart Failure Self-Care

The concept of women perceiving their heart failure situation to be different than males has been qualitatively investigated for a number of years. In an early qualitative study, Mårtensson, Karlsson and Fridlund (1998) used a phenomenological approach to explore how women perceived their experience living with heart failure**.** Through semi-structured interviews, researchers discovered a number of themes specific to women including feelings of: content, limitation, anxiety, support, and powerlessness. This early qualitative study began to identify the

importance of research that is primarily focused on the unique needs of women with heart failure.

Gary (2006) investigated the self-care practices of women specifically with diastolic heart failure. Semi-structured interviews were conducted in the homes of 32 women affected by diastolic heart failure. It was discovered that almost half of the women interviewed did not weigh themselves every day, a fundamental self-care maintenance behavior. Food and dietary restrictions had a great influence on the participants in the study. Women were found to not add additional sodium to foods; however, they had difficulty with identifying prepared foods high in sodium. Dining at restaurants and preparing foods for their families were considered highly valued. Women expressed discontent with the level of fatigue associated with heart failure and considered themselves a burden to friends and family. These factors made it difficult to cope with a heart failure diagnosis. It was suggested by the author that interventions to improve heart failure self-care in women should include both physical activities and evaluations of social support.

Using a descriptive, phenomenological approach, Allen, Arslanian-Engoren, and Lynch-Sauer (2009) discovered similar findings in a pilot study that examined the lived experience of four middle-aged women with heart failure. The women described major lifestyle and role changes, overwhelming fatigue and feelings of depression and frustration. Women in this pilot study described five themes: (1) developing a new concept of self, (2) conceding physical limitations, (3) enduring emotional heartache, (4) accepting support and (5) rejuvenating through rest. Health care providers, specifically nurses, are called on to perform preventative screening for depressive symptoms and ensure women with heart failure have adequate support.

Thomas and Clark (2011) conducted a systematic review of six qualitative studies investigating how sex and gender influence heart failure self-care. Overwhelming physical limitations, changes to social and gender roles, and the importance of social support and relationships were all identified as important themes affecting heart failure self-care in women. Contrary to previous studies, the authors discovered women in the reviewed studies had lower self-care confidence and more negative emotions regarding their diagnosis. These negative emotions affected a women's well-being and her heart failure self-care practices.

Riegel, Dickson, and Topaz (2013), conducted a qualitative analysis of how individuals make decisions regarding their self-care based on the theory of naturalistic decision making (NDM). The authors describe individuals having experience with heart failure symptoms and using these experiences to make appropriate decisions to treat the heart failure symptoms. In a previous study, (Riegel et al, 2010) it was discovered that women tend to seek more advice from family, friends, and health care providers when making decisions about the treatment of their heart failure symptoms. In this qualitative analysis, authors concluded uncertainty, ambiguity, urgency, illness characteristics, and the involvement of others may be more influential in decision making, rather than gender differences. Self-care maintenance behaviors, or the everyday practices one must undergo to maintain a state of wellness, does not involve the decision making process one experiencing a heart failure exacerbation undergoes. The conclusions of the authors may not be applicable to women in the heart failure self-care maintenance phase of the heart failure self-care process. This supports the further investigation into the specific factors which influence heart failure self-maintenance behaviors.

Self-care maintenance immediately precedes self-care management behaviors. Both are essential to successful heart failure self-care. Wingham, Harding, Britten and Dalal (2014) used

the qualitative synthesis methods of meta-ethnography to suggest a conceptual model of heart failure self-care management strategies. It was suggested that patients living at home with heart failure undergo a five step process: (1) Disruption, (2) Sense making, (3) Reaction, (4) Response, (5) Assimilation. It is through this process that an individual transitions from coping with the impact of a heart failure diagnosis on social relationships and the physical and psychological symptom experience (disruption) to self-reflecting and eventually making necessary lifestyle changes (Wingham et al., 2014).

In a methodologically similar study, Harkness and colleagues (2015) used the meta-synthesis approach proposed by Noblit and Hare to gain a deeper understanding of the strategies heart failure patients use when incorporating self-care behaviors into daily life. The authors' synthesized qualitative data from 47 previously published studies and divided self-care strategies into two divisions: perception-based and action-based. Perception-based strategies include responses that are emotional in nature and those that involve cultural beliefs/norms and spirituality. Action-based strategies encompassed the adjustment of the daily routine to conserve energy and decrease daytime fatigue and communication with healthcare providers. Heart failure self-care was also reported to be an ongoing learning process and many times, an individualized approach to heart failure self-care education is essential.

Many of the same findings were reiterated in a 2014 meta-synthesis that focused on contextual factors in heart failure (Strachan, Currie, Harkness, Spaling & Clark, 2014). Similar to previously reported findings from qualitative studies with a meta-synthesis approach, the involvement of caregivers/social support, financial capacity and lifestyle changes were identified as important heart failure factors. In addition, authors of this meta-ethnography focused on the impact of gender and how women tended to support others rather than accept the support being

offered. Women also benefited from heart failure educational sessions and were able to use heart failure education to effectively bridge the gap between symptom awareness, recognition/interpretation and treatment (Strachan et al., 2014).

Mixed Methods Studies of Heart Failure Self-Care

Defining gender roles in heart failure was the goal of a 2011 mixed methods study published by Dickson, et al. It was determined that individuals with heart failure may perceive their role as active, passive or collaborative with heart failure self-care practices. Those perceiving an active role understood heart failure self-care as their primary responsibility and were proactive in meal planning and titrating diuretic dosage. Those who tended to collaborate with family or healthcare providers did not make independent decisions regarding heart failure self-care. Reliant individuals took the most passive role in heart failure self-care and depended on others to make self-care decisions for them.

Women with perceived active roles scored higher on the SCHFI than men with perceived active roles in all three domains (Dickson et al., 2011). However, women in an active role collaborated more with healthcare providers than their male counterparts. Males were described as having an active role in heart failure self-care, often making their own, independent decisions without the guidance of a healthcare provider. It was hypothesized that males take on a more active role in heart failure self-care to maximize control over a situation and demonstrate masculinity. The idea of masculinity is a key concept in gender identity, and a cultural factor that has been shown as a way of determining health related practices (Jack, 2005). Although more women were found to be in a collaborative role, scores on the SCHFI reflected women obtained a higher self-care maintenance score and there was a non-significant trend towards a higher self-care management score. Overall, individuals who believed they had an active heart failure self-

care role had better self-care scores than those who believed they had a collaborative or passive role.

Riegel et al. (2010) used a mixed methods study to identify and describe gender specific barriers and facilitators to heart failure self-care. Patients first participated in a semi-structured interview. Qualitative interview data were then confirmed using a quantitative survey (SCHFI). The authors of this study found no consistent gender differences in self-care maintenance scores or distinct differences in management scores, however; the barriers and facilitators that affected the choice of self-care behaviors tended to be gender-specific. Women reported higher self-care management scores; however, this difference was not statistically significant, as only a portion of the sample had experienced symptoms necessary for management behaviors. Women reported better emotional support than men, yet men reported better tangible support from spouses and children. In the sample included in this study, women were more likely to be widowed and living alone. Men were also found to be more depressed when measured quantitatively, although this difference was not statistically significant.

How expertise in heart failure self-care develops is essential for healthcare providers to understand. Using extreme case sampling, Riegel et al., (2007) used qualitative and quantitative methods to determine what made an individual “poor,” “good,” or an “expert” in heart failure self-care practices. Qualitative interviews were first conducted to determine the process in which heart failure self-care expertise develops. Participants were then given instruments to quantitatively measure this expertise. Using only the qualitative data, an investigator determined the level of expertise and categorized patients into one of the three classifications. Those who were poor in self-care did not perform maintenance behaviors on a daily basis and failed to react to a symptom of a heart failure exacerbation. Individuals deemed experts in heart failure self-

care adequately managed their symptoms and were active in maintenance behaviors. Experts in heart failure self-care showed evidence of routine maintenance behaviors and knowledge in self-care management practices. In a total sample of 29 individuals, only three individuals, all of whom were female, were categorized as experts in heart failure self-care. These experts were found to have a better and deeper understanding of medications, had stronger social support and were generally more symptomatic, while depression was highest in those who were poor in self-care.

It was determined in a 2008 mixed methods study that a third typology, inconsistent, existed. Individuals fitting this description had experience with heart failure self-care management but had not yet possessed the skills to correctly and consistently respond to symptoms. Individuals that were inconsistent in self-care management behaviors were less vigilant over time, had higher rates of cognitive impairments and were discordant. This study used the SCHFI to quantitatively identify "experts," "notices," and those that are "inconsistent" in heart failure self-care. Out of a total sample of 41 individuals, six were experts, six were novices and 29 fit the description for inconsistent. Novices lacked experience, skill and had diminished self-efficacy yet maintained a positive attitude about the diagnosis. Conversely, experts had the necessary experience, skill and self-efficacy for adequate self-care management. Inconsistent individuals had a range of attitudes and skills but all lacked the necessary self-confidence (Dickson et al., 2008).

Based on a review of literature, there is conflicting information regarding heart failure self-care maintenance practices of women, and no studies have focused exclusively on these behaviors. The present study aims to close this gap in the literature by assessing the facilitators and barriers that women face when performing heart failure self-care maintenance behaviors.

Use of the mixed methodology may aid in facilitating the generation of new hypotheses, identifying new relationships between variables and provide a strong link between theory and practice. Identifying these factors will aid in the development of more specific and individualized interventions to improve heart failure self-care.

Contributions to Nursing Science

This study contributed to nursing science through the following ways:

1. Isolating the specific self-care maintenance behaviors of women to better understand the factors that facilitate and/or impede these behaviors.
2. Measuring the level of self-care confidence in women with heart failure and how this level of confidence positively or negatively affects heart failure self-care maintenance behaviors.
3. Potentially identifying previously unrecognized factors that affect heart failure self-care maintenance behaviors in women.

Summary

This chapter presented a literature review of current studies that utilize quantitative, qualitative, and mixed methods. Studies that used the SCHFI were of particular focus. Previous studies have demonstrated the wide variety of contributing factors to heart failure self-care. While many studies, conducted both internationally and domestically, have focused on heart failure self-care behaviors, there are minimal conclusions drawn that are specific to the female population and specific to self-care maintenance behaviors. This gap in the literature supported this study's investigation and contributed to the novelty of the study design.

The mixed methods approach required rigor in both the quantitative and qualitative design. Chapter three will provide an in-depth presentation of the methodology used in each step

of this study's design. Inclusion criteria, participant setting/sample, and study procedures are explained.

Chapter 3: Methods

Introduction

This chapter will present a detailed outline of the methods and procedures used in the study. Quantitative and qualitative research strands of the mixed methods design are described. The procedures for protection of human subjects, Institutional Review Board processes, participant recruitment, procedures for quantitative collection and analysis as well as qualitative data collection and analyses are presented. Threats to validity and integrity to the study are also identified.

The following research questions guided this study:

1. What is the distribution of self-care maintenance in women with heart failure?
2. Is there a correlation between high and low scores in heart failure self-care maintenance and high and low scores in heart failure self-care confidence?
3. What are the different factors that can be identified which facilitate or impede heart failure self-care behaviors in women scoring adequately or inadequately on the Self-Care of Heart Failure Index (SCHFI)?
4. What are the motivating factors that influence heart failure self-care behaviors in women who score adequately and inadequately on the SCHFI?
5. In what ways do the interview data that investigate self-care in women with heart failure help to explain the quantitative results about self-care maintenance and the influence of self-care confidence in both those scoring adequately and inadequately as reported on the SCHFI?

Design

In this mixed methods study, a convergent design was used (Creswell, 2015). This research methodology is best for comparing and contrasting quantitative data with qualitative finding. Convergent designs are also best used to develop a deeper understanding of a phenomenon when there is equal value in both the quantitative and qualitative data. Following the methodology of this design, the study was conducted in one phase. In the quantitative strand of the study, a demographic questionnaire and the SCHFI were distributed to eligible patients being treated at a primary care clinic of an urban hospital. At the conclusion of collecting quantitative data, participants were invited to participate in the qualitative strand which consisted of a semi-structured, qualitative interview. A visual representation of this methodology is displayed in Figure 3.

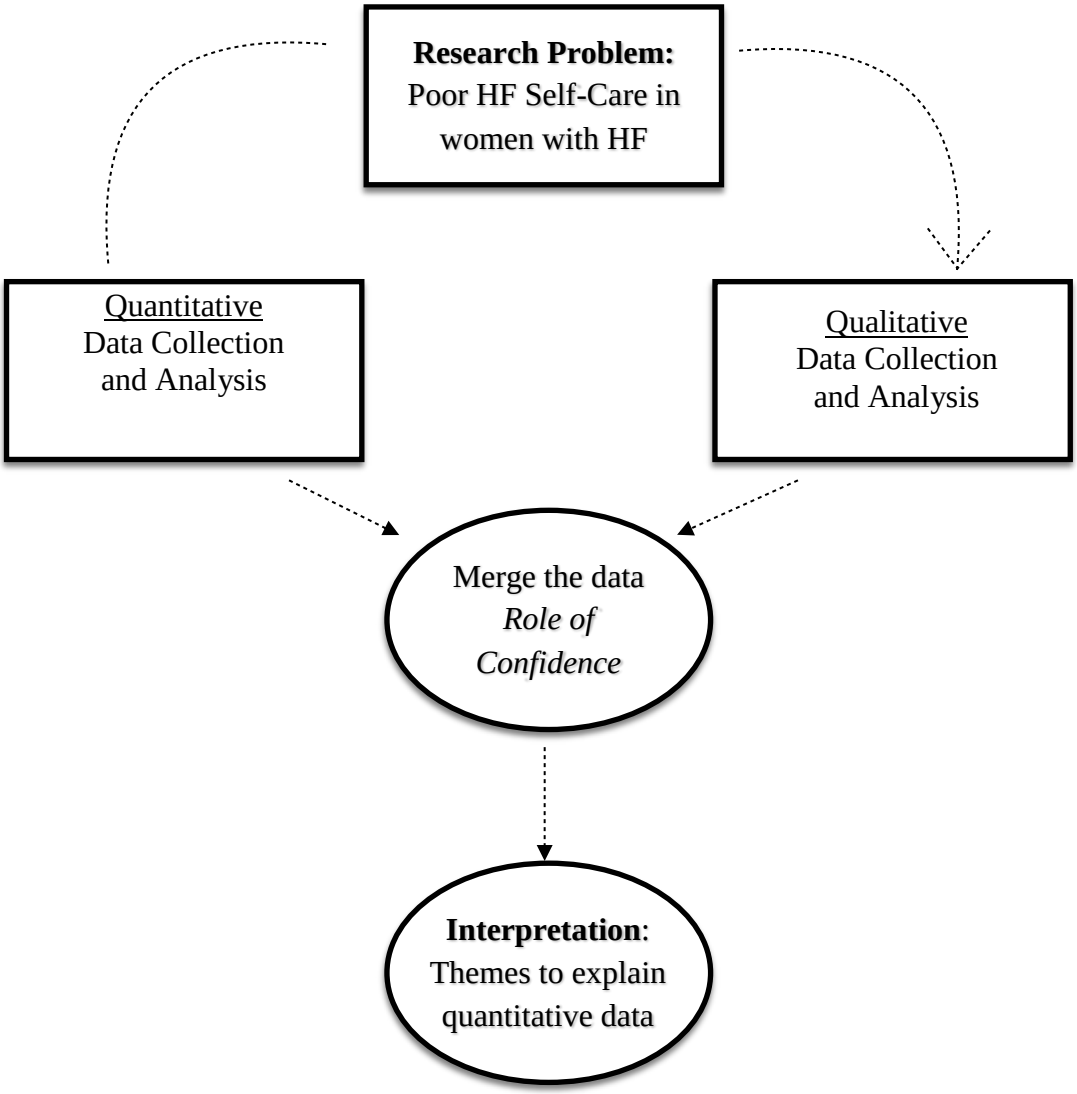


Figure 3: Diagram of the Convergent Mixed Methods Design

The semi-structured interviews were conducted using open-ended questions to further expand on the data obtained from the quantitative survey. The overarching purpose of this research design was to use the qualitative findings to further explain the initial findings discovered through the quantitative strand (Creswell, 2015). Because the majority of new information was learned through the semi-structured interviews, the qualitative phase of this study held the dominance.

At the completion of the quantitative strand and the qualitative strand, data were combined to answer the mixed methods research question. Interviews with those participants who had inadequate heart failure self-care were compared to the interview data of those who scored adequately for heart failure self-care maintenance behaviors. Trends were identified and interview data were compared with survey responses on the SCHFI.

Inclusion Criteria

Inclusion criteria for this study were: (1) English-speaking women over the age of 21, (2) have a diagnosis of heart failure, (3) currently receiving care at the heart failure clinic of the participating hospital, (3**)** living at home or in an environment which requires the independent performing of daily self-care maintenance behaviors, and (4) willing and able to participate in the study. A diagnosis of heart failure for longer than 6 months was also required to provide adequate reflection on daily heart failure self-care maintenance practices.

Setting

The setting for this study was a primary care clinic associated with an urban hospital system. It was estimated that the clinic sees approximately three to five heart failure patients a day. Many of the patients that are seen at the clinic rely on Medicaid or Medicare to fund their healthcare costs and are seen in the immediate post-discharge period.

Sample

The target population for this study was women with heart failure. No specific age, race, ethnicity, level of education, or living situation was targeted. Every effort was made to recruit an ethnically diverse sample of women**.**

Participant Recruitment

Patients with heart failure typically attend the heart failure clinic biweekly on Tuesdays and Thursdays. A registered nurse (RN) from the clinic who is responsible for conducting heart failure teaching and education initially introduced the study to eligible women on a biweekly basis and as the opportunity presented. This RN was chosen because of her previously established relationship with the patients and knowledge of clinic procedures. The clinic RN explained the purpose of the study and invited women who met the established eligibility criteria to participate. The clinic nurse used a script that was prepared by the researcher to ensure consistency in recruitment procedure (Appendix 1). Patients who verbalized an interest in participating in the study were then asked to provide a contact telephone number for follow-up by the researcher.

The researcher was responsible for further screening the patients for eligibility based on the presented criteria. The participant was then directly contacted to review the study protocol and obtain informed consent. During this contact, the researcher answered any questions and invited eligible patients to participate in the study at a time and place convenient for the participant or via telephone.

For those patients choosing to schedule an in-person appointment, a meeting between the researcher and the participant was arranged. All in-person meetings took place in the participant's home residence. After informed consent was obtained, the researcher distributed the SCHFI (Appendix 2) and demographics survey (Appendix 3) to the participant. Immediately following the completion of the surveys, the researcher verbally confirmed permission to turn on an audio recorder and began to ask the qualitative interview questions. Interviews ended when all questions had been explored and the participant offered no new information.

For those participants choosing to participate via telephone, the researcher asked each question on the SCHFI and demographic survey verbatim. Immediately after the quantitative data were collected, the researcher informed the participant the next portion of the interview would be audio recorded. Immediately following all interviews, both in person and via telephone, the researcher transcribed the audio recordings into a document which was password protected.

Ethical Considerations

Prior to data collection, approval from the Institutional Review Boards (IRB) of the University of Connecticut and of the associated hospital system was obtained. All amendments and extensions to the research protocol were IRB approved. Informed consent was sought from each study participant and it was explained that participation in the all aspects of the study was voluntary and withdrawal from the study could occur at any time. All patients were assured that every attempt to uphold strict confidentiality standards were maintained throughout the study process and were informed of the purpose and benefits of participating in the study. Participants were also informed that the study posed minimal risk and would not interrupt their current treatment plan.

Study Procedures for Quantitative and Qualitative Strands

Data collection occurred from January 2015 through April 2016 and was conducted according to the established research protocol. First, the researcher provided an introduction of herself and the study to each participant to establish rapport and create an environment of trust. The purpose and rationale for the study were explained and any preliminary questions were answered directly by the researcher to the participants. Informed consent was then obtained.

The SCHFI was then presented to each participant. In the cases where data were collected in person, participants were encouraged to read each question thoroughly and were only assisted if there was a difficulty regarding comprehension of the survey question. For the participants completing the survey via telephone, each SCHFI question was read verbatim along with the Likert scale choices. At the completion of the SCHFI, all participants were presented with the demographics questionnaire. Similar to the SCHFI, the demographics questionnaire was read verbatim for those participating via telephone.

Following the collection of all quantitative data, participants were asked to participate in a semi-structured interview that highlighted their everyday heart failure behaviors and the motivations behind these behaviors. All interviews were audio recorded for accuracy. All quantitative data were entered into SPSS version 24. Interviews were transcribed verbatim by the researcher. Following the convergent design, all participants were interviewed until qualitative data saturation was reached. Data were then organized into common themes. These themes guided the researcher in identifying differences and commonalities in those who scored adequately and those who scored inadequately on the SCHFI instrument. Themes were then compared with the quantitative database and results of both the quantitative strand and qualitative strand were integrated.

Quantitative Strand Sampling

The sampling strategy that was used in this study was based on published scoring criteria by the authors of the SCHFI as well as personal correspondence with Dr. Barbara Riegel, the lead author of the SCHFI. For the present study, total scores on the SCHFI guided the allocation of the patients into one of two groups. Participants scoring 69 or lower were categorized as

inadequate in self-care and participants scoring 70 or greater were considered adequate in self-care.

Instrumentation

Demographics

A demographic questionnaire (Appendix 3) was used to create a profile of study participants. Information such as age, gender, race, ethnicity, marital status, living arrangements, and educational level was collected.

The Self-Care of Heart Failure Index (SCHFI) Version 6.2

The Self-Care of Heart Failure Index (SCHFI) (Riegel et al., 2004**)** is a 22-item instrument established to measure the level of heart failure self-care. Using a 4-point Likert scale, the SCHFI measures the three domains of heart failure self-care: maintenance, management and confidence. The items which measure maintenance focus on the daily tasks associated with heart failure including medication, dietary and treatment adherence. The management sub-scale addresses the ability of the individual to recognize and choose an appropriate treatment when a heart failure exacerbation occurs. The patient's perceived ability to self-monitor and self-manage is assessed through the confidence sub-scale. A standardized, summative score of greater or equal to 70 is defined as adequate heart failure self-care (Vellone et al., 2013).

The instrument was first published in 2004 as a 15-item questionnaire and scores were calculated as a summative score across the three domains. Since its publication, the SCHFI has become the most widely used instrument to assess self-care in heart failure patients. It has been used in a number of heart failure self-care related studies (Lee et al., 2009; Riegel et al., 2007;

Dickson et al., 2011). The SCHFI has been used in at least 25 different countries (Riegel et al., 2009). Original psychometric tests showed reliabilities of .56, .70, and .82 for the maintenance, management and confidence sub-scales, respectively (Riegel et al., 2004**)**. Reliability coefficients (Cronbach's alpha) are measured on a scale of 0-1 with higher measures indicating a higher level of internal consistency (Polit & Beck, 2017).

An update to the SCHFI yielded changes to the scoring process of the instrument and refined weak items (Riegel et al., 2009). The maintenance scale was revised to reflect best and recommended practices for heart failure self-care, such as obtaining a daily weight. Original psychometric testing yielded a low self-maintenance alpha (.56) which the authors attributed to the low number (5) and variety of questions in the maintenance domain. Five additional questions were added to the self-care maintenance sub-scale to address edema, communication with healthcare providers, and medication adherence. Two items were also added to the self-care confidence sub-scale (Riegel et al., 2009).

It is recommended by the authors to score each sub-scale independently and calculate a standardized score. Evaluating each score separately allows for researchers to evaluate both asymptomatic and symptomatic patients. Psychometric testing was again completed with community-dwelling individuals diagnosed with heart failure. The updated instrument coefficient alphas were calculated to be 0.55, 0.59, and 0.82, respectively. Less than ideal coefficients are again attributed to significant differences in responses from the same individual as heart failure symptoms can be highly variable. Because these coefficients are a measure of internal consistency, the authors of the SCHFI expected a low alpha because the self-care maintenance sub-scale measures a variety of heart failure behaviors with no correlation such as daily weight and routine exercise. Although these behaviors are self-care maintenance behaviors,

an individual may include one in their daily practices while omitting the other. This is pertinent information to self-care maintenance behaviors but does not translate into a sufficient alpha measurement (Riegel et al., 2009).

Authors compared the validity of the SCHFI to other instruments measuring heart failure self-care such as the European Heart Failure Self-care Behavior Scale (Lee et al., 2013), which also uses a Likert-type scale and found them to be similar. Construct validity was tested using confirmatory factor analysis which found the overall model of fit of the SCHFI v6.2 to be adequate ($x^2 = 356.92$) (Riegel et al., 2009) and similar to earlier versions of the SCHFI (v4: x^2 329.9). Further testing of the SCFHI was done in 2013 using structural equation modeling to further investigate the relationships between symptom monitoring and recognition, treatment adherence and implementation. Authors found evidence of construct validity within the SCHFI v6.2 as well as contrasting groups' validity, internal consistency and test-retest reliability (Vellone et al., 2013). The authors call for more investigation and further validation of the tool to be completed with more female patients (Riegel et al., 2009).

Qualitative Strand Sampling

The nature of the mixed methods study was to explain and to understand using multiple methodologies of both quantitative and qualitative nature. Thus, the sampling plan was more reliant on data saturation of the qualitative themes rather than sample size. The researcher continued to conduct semi-structured interviews with participants until data saturation was achieved in both the inadequate and adequate self-care groups. Data saturation was determined when no new knowledge or ideas were emerging through the qualitative interview.

Two groups (those with adequate self-care and those with inadequate self-care) were interviewed using the same interview questions to gain a deeper understanding of heart failure

self-care maintenance behaviors across a broad spectrum. Gaining a deeper understanding of self-care maintenance behaviors across a wide range of self-care maintenance scores may aid in the discovery of new factors which may positively or negatively affect heart failure self-care.

Procedure for Quantitative Data Collection

All participants completed the Self-Care of Heart Failure Index version 6.2 (Appendix 2). It is recommended from the instrument's authors that each domain is scored and interpreted separately. This allows for all patients to complete the instrument without the effect of symptomatology. To account for the possibility of a patient not completing the self-care management construct due to experiencing a lack of symptoms, all scores are standardized to a 0 to 100 score. Each construct is interpreted independently, rather than a total score (Riegel, 2015)

In this mixed methods sample, Cronbach's alpha for the self-care maintenance scale was 0.64, self-care management was 0.71 and self-care confidence was 0.77. These values are slightly higher than the averages on the constructs of 0.55 for self-care maintenance and 0.60 for self-care management. Self-care confidence was slightly lower than the calculated average of 0.83 (Barbenelli, Lee, Vellone, & Riegel, 2014).

Procedure for Qualitative Data Collection

After completion of both quantitative surveys, patients were invited to participate in a semi-structured interview to better understand their everyday behaviors of heart failure self-care. Interview questions were: (1) Please tell me about your heart failure daily practices, (2) What influences your daily heart failure practices and (3) What influences your confidence in performing heart failure daily practices? When appropriate, probing questions were used to extract more information from the participant. Examples of probing questions are: (1.) Can you

please tell me more about that, or (2) Can you please give me an example of what you are describing?

All qualitative interview sessions were audiotaped and transcribed verbatim by the researcher. Of the 24 interviews, 11 were conducted in person and 13 were conducted via telephone. Qualitative data that were generated from the three, open-ended questions were analyzed using Krippendorff's (2013) method of content analysis. Interviews ranged from approximately five minutes to thirty minutes. A detailed audit trail including time and date of the interview as well as if the interview was conducted in person or via telephone was kept by the researcher.

Procedure for Quantitative Data Analysis

Descriptive statistics, including measures of averages and standard deviations were calculated for the demographics profile. Pearson's correlation (*r*) was calculated to determine any significant relationships between the self-care maintenance and self-care confidence variables. A quadratic regression analysis was performed to detect any non-linear relationships between self-care maintenance and self-care confidence. Independent samples t-tests and measurements of chi-squared were performed to detect any significant differences in means.

Procedure for Qualitative Data Analysis

Krippendorf's method of content analysis was used as the qualitative research technique. By definition, content analysis is reliable and replicable and generates valid scientific results (2013). The transcripts from the qualitative interviews were used to create clusters of similar data. According to Krippendorf (2013), clustering is the formation of a whole from singular ideas that are connected or that belong together. Identified clusters were then organized and

categorized into a dendrogam; a tree-like diagram that visually represents the merging of data together into common themes (Table 7).

Procedure for Integrating the Data (Mixed Methods Strand)

To complete the data integration process, the researcher examined the quantitative scores and compared them to the qualitative transcripts. Scores on the SCHFI were compared with the coded interview data to determine any inverse or direct relationship. Side-by-side comparison was conducted throughout the merging process. Quotes from the qualitative interviews were used to further solidify and understand the quantitative results. The comparisons were articulated and the researcher interpreted the mixed results. Finally, the results of the data analysis from both the quantitative and qualitative strand were interpreted.

Threats to Qualitative Internal Validity

Rigor of qualitative methods was examined and potential threats to the integrity of the study were identified and addressed. Throughout the duration of the study, there were no notable mainstream news or media developments related to heart failure that could be considered a potential threat to the study's internal validity. The researcher also recognized that certain variables such as time since first diagnosis, living arrangements, marital status, etc., may affect study outcomes. Information regarding these variables was collected and reported through the demographic information. Although all women with heart failure were invited to participate in the study, the researcher recognized that those who were willing to participate may have an added interest in heart failure and heart failure related care and that these factors may possibly affect study outcomes.

Threats to Quantitative External Validity

Collecting quantitative data from the SCHFI prior to interview data may have influenced the participant's qualitative interview. Because the first interview question was an open-ended question regarding a patient's everyday behaviors, many patients reported behaviors that are measured through the first construct of the SCHFI. These behaviors are the evidence-based practices which heart failure patients are educated to conduct on a daily basis. The small sample size from the selected population may be another perceived threat to external validity and a limitation to the study as only one clinic was used. This particular and convenient patient population may not be representative of the greater heart failure patient population. Because the majority of data collection took place via telephone, the researcher ensured it was a convenient time for the patient to talk in order to minimize distractions and interruptions.

Threats to Integrity

The researcher clearly defined essential concepts and consistently applied these definitions throughout the research study. Adhering to the methodologies as defined by Creswell (2015) for mixed methods and by Krippendorf (2013) for the qualitative analysis ensured reliability of the data that were generated. Recognizing one's own biases is an important component of qualitative investigation and the researcher practiced reflexivity when interpreting the interview narratives (Beck & Gable, 2012). Consultation with experts in qualitative analysis occurred periodically and a comprehensive audit trail was kept for the duration of the study.

Data Management

The researcher ensured the privacy and confidentiality of all data by storing all study records (including any codes to data) in a locked and secure location. Research records were labeled with a unique code for each participant. The code was derived from a sequential 3 digit number that reflected how many people had been enrolled in the

study. A password protected, master file that linked names and codes was maintained in a separate, secure location. This master file will be destroyed after 3 years. All electronic files (e.g., database, spreadsheet, etc.) containing identifiable information were password protected. Any computer hosting such files also had password protection to prevent access by unauthorized users. At the conclusion of this study, the researcher may publish the study findings. In this case, information will be presented in summary format and will not identify individual participants in any publication or presentation.

Summary

This chapter presented the sampling, data collection and data analysis procedures for the quantitative, qualitative and mixed methods phases of the study, as well as information regarding the protection of human subjects. Mixed methods methodology and study procedures were also outlined. Potential threats to external and internal validity and integrity of the study were also described.

Results from the quantitative, qualitative, and mixed methods strands are presented in Chapter 4. A full report of participant demographics, summary statistics and formal statistical tests obtained from the SCHFI are presented in the quantitative strand. Data obtained through qualitative investigation including the factors that both facilitate and impede heart failure self-care behaviors are also explained in Chapter 4. Findings from the mixed methods strand and from integration of results conclude the chapter.

Chapter 4: Results

Introduction

This chapter will present the findings of this mixed methods study that was designed to address the varying heart failure self-care behaviors of women living with heart failure. This study held a specific focus on the everyday, self-care maintenance tasks as defined by the Self-Care of Heart Failure Index (SCHFI) version 6.2. There were two primary aims of this study: (1) to identify key differences in women who display an adequate level of heart failure self-care maintenance behaviors as compared to women who scored inadequately as defined by the SCHFI v6.2 and (2) to explore the effect of self-care confidence as measured by the SCHFI and its impact on individuals of both adequate and inadequate heart failure self-care. Adequate heart failure self-care was defined as a score of greater than or equal to 70 and inadequate self-care was defined as a score of less than or equal to 69. A demographic profile of the study participants and relationships between study demographics and data generated from the SCHFI will be presented within this chapter.

This chapter will describe the sample and findings of the quantitative, qualitative, and mixed-methods results from the study. Results generated from this study will be presented as they relate to each of the five stated research questions.

Data Collection

After confirming a heart failure diagnosis and ability to actively participate in the study, patients were invited to participate and informed consent was obtained through the process described in chapter 3. The SCHFI and demographic surveys were administered either in person or via telephone. In the cases that the surveys were administered in person, the interview was conducted in a private room to ensure privacy for the participant. The researcher was available to

address any questions or concerns. For the cases in which the surveys were completed via telephone, the researcher ensured that it was a convenient time for the participant and there would be adequate time to complete the surveys. If the participant was unavailable at the time of the initial phone call, a brief message introducing the study and the contact information of the researcher was left. No personal information was addressed via telephone message. Every attempt was made to contact each patient that was deemed eligible for the study.

Throughout the months of January 2015 through April 2016, 55 patients were deemed eligible to participate in the study. This number was lower than the projected patient estimates. Fluctuations in clinic census, changes in clinic staff, and difficulties with patient follow up were reasons cited for the low patient recruitment. Twenty-four patients opted to not participate in the study citing reasons such as time constraints and disinterest in the study. In total, 31 patients completed the quantitative strand of the study. Of these, 24 patients completed the qualitative strand. Qualitative data was collected until data saturation was reached and no new information emerged through the interview process. One participant declined to complete the interview stating that she was "…too tired," to participate. This participant was offered additional time and a rescheduling of the qualitative interview; however, she continued to decline the invitation (Personal communication, participant #10, August 28, 2015).

Quantitative Results

Data Analysis

Descriptive statistics including frequencies, means, and standard deviations were calculated to describe the demographic characteristics of the study participants. Independent samples t-tests, chi-squared tests, and Pearson's correlation (*r)* were used to detect relationships between demographic and survey data variables. A quadratic regression analysis was calculated

to investigate a non-linear relationship between self-care maintenance and self-care confidence variables. For all quantitative analyses, a *p*-value of $\leq .05$ was set as the level of significance.

Demographic Profile

A total of 31 women participated in the study. The mean age of the sample was nearly 58 years of age (SD ± 10.1 years). Time since first heart failure diagnosis ranged from less than a year up through 20 years with an average of approximately 5 years. African American women comprised over 75% of the sample and most women were unemployed (77%), unwed (single, divorced or widowed) (86%), with a high school education (74%). The majority of the sample also lived with someone else (68%) (Table 2).

Table 2: Demographic profile of Participants

Variable	Mean (SD)/ Range [Min-Max]	N (%)
Age (years)	57.9 (10.1) / 30 - 79	
Years with HF	5.3 (4.7) / 0 - 20	
Race		
White		9 (29)
African American		21 (77)
Undisclosed		1 (3)
Employment Status		
Full Time		2 (6)
Retired		5 (16)
Unemployed		24 (77)
Marital Status		
Single		10 (32)
Married		4 (13)
Divorced		6 (19)

Widowed		11 (35)
Education		
Grade School		2 (6)
High School		23 (74)
Bachelor's Degree		6 (19)
Living Arrangements		
Alone		10 (32)
With Someone Else		21 (68)

A demographics profile dividing those participants scoring adequately on the SCHFI ($\geq$ 70) and those scoring inadequately on the SCHFI ($\leq$ 69) is displayed in Table 3. Participants scoring adequately (n=11) and inadequately (n=20) were similar in age (57.5 ±12.3 versus 58.1 ±9, respectively) and had similar years of experience with heart failure (5.3 ± 4.3 versus 5.4 ±5, respectively). Participants that scored inadequately tended to live with someone else (75% versus 54.5%). Independent samples t-tests and chi-squared tests were performed on the demographic variables. There were no statistically significant differences between groups, except for differences in employment status (p = .01) (Table 3).

Table 3: Demographic Profile: Adequate Vs. Inadequate

Variable	Mean (SD)	N (%)		*p*-value
Age (n)				
Adequate (11)	57.7 (12.3)			.58
Inadequate (20)	58.1 (9)			
Years with HF	5.3 (4.3) / 1 - 15			.66
Adequate	5.3 (4.3)			
Inadequate	5.4 (5.1)			
		≥ 70	**≤69**	***p*-value**
Race				.52
White		3 (27.3)	6 (31.6)	
African American		8 (72.7)	14 (70)	
Employment Status				.01
Full Time		0 (0)	2 (10)	
Retired		1 (8.3)	4 (20)	
Unemployed		10 (83.3)	14 (70)	
Marital Status				.65
Single		3 (27.3)	8 (40)	
Married		3 (27.3)	7 (35)	
Divorced		3 (27.3)	1 (5)	
Widowed		2 (18.2)	4 (20)	
Education				.14
Grade School		2 (18.2)	0 (0)	
High School		8 (72.7)	15 (75)	
Bachelor's Degree		1 (9.1)	5 (25)	
Living Arrangements				.61
Alone		5 (45.5)	5 (25)	
With Someone Else		6 (54.5)	15 (75)	

Power Analysis

Computer software (G* Power, version 3.1) was used to calculate a post hoc power analysis and estimated effect size. This was done to evaluate the potential for Type 2 errors in statistical testing. A Type 2 error occurs when the researcher fails to detect a significant test result when an association between variables really exists (Ellis, 2010). Post hoc analysis showed an estimated effect size for the quantitative strand was calculated to be 50% and an estimated power to be 30%. A total sample size of 102 was required for the sample to have an adequate estimated effect size of 0.8. With an estimated effect size of 80%, there is a 20% risk of a Type 2 error occurring, which is considered acceptable (Polit & Beck, 2017).

Research Question 1:

What is the distribution of self-care maintenance in women with heart failure?

To determine the distribution of self-care maintenance scores, descriptive statistics including means, percentages, and standard deviations were calculated. Analysis revealed the mean value for the self-care maintenance score was 61.1 (±15.5) with a range of 17-87 (Figure 4). A score of greater than or equal to 70 is defined as adequate self-care; scores that are equal to or less than 69 were defined as inadequate according to the instrument parameters set by the lead authors of the SCHFI. The majority of the participants in this study (70%, n = 22) scored inadequately as defined by the SCHFI. The distribution of SCHFI scores is displayed in Figure 4.

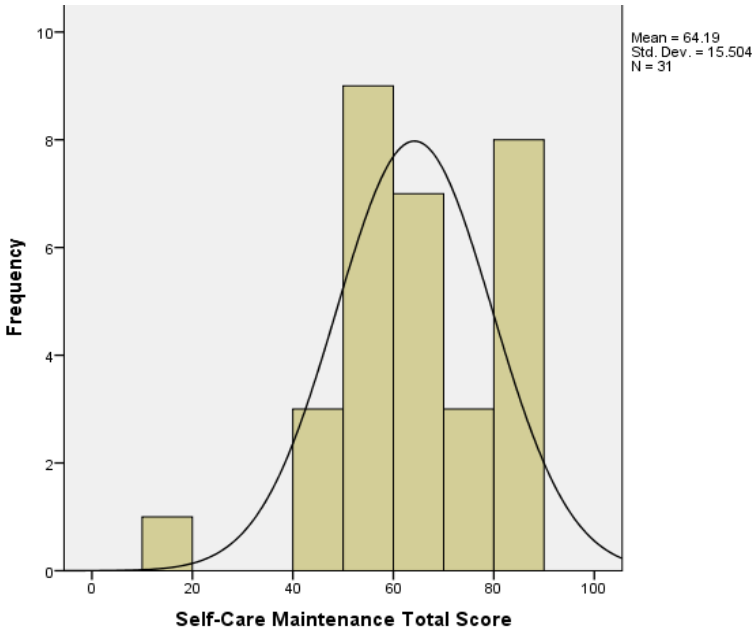


Figure 4: Distribution of Self-Care Maintenance Scores

The histogram display of the distribution of data demonstrates a bimodal pattern, indicating two distinct groups among the participants. This reflects the division between those scoring adequately and those scoring inadequately on the SCHFI. There was one outlier in the data set. Outliers are values which occur outside the normal range of the data set (Polit & Beck, 2017). One participant scored a 17 on the SCHFI self-care maintenance scale, indicating an abnormally low score. For certain statistical analyses, including the calculation of a quadratic regression, the outlier was removed from the full data set to reduce its potential biasing effects.

Research Question 2: Results

Is there a relationship between high and low scores in HF self-care maintenance and high and low scores in HF self-care confidence?

First, mean scores for heart failure self-care maintenance in those scoring adequately (M = 80.1, SD = 6.1) and inadequately (M = 55.5, SD = 11.6) were calculated. Self-care confidence scores in both those scoring adequately (M = 67.3, SD = 15.1) and inadequately (M = 74.5, SD = 16.4) were also determined. An independent samples t-test showed there was no statistical difference between these two means of self- care maintenance scores (t (29) = -6.57, p = .18) self-care confidence scores (t (29) = -1.23 , p = .56).

Next, a Pearson's correlation (r) was calculated to determine whether there was a linear relationship between self-care maintenance and self-care confidence scores. A weak, positive correlation was observed, (r [29] =.19, p = .30), however this correlation was not statistically significant.

A scatterplot of the data displaying the distribution of self-care maintenance and self-care confidence scores was generated to better visualize the relationship between the data points. Because the Pearson's correlation (r) between self-care maintenance and self-care confidence was not statistically significant, further investigation using a quadratic regression equation ($Y=a+b_1X+b_2X^2$) was performed. In this equation, b_1 and b_2 are constants for the independent variables (Table 4). The curved line generated from this equation was fit over the scatterplot. The values for the SCHFI self-care confidence were centered at 65 and squared. These independent variables were centered at 65 because that was the lowest point of the parabola (Figure 5). This regression calculation was used to show the significant, parabolic relationship between self-care maintenance and self-care confidence (R^2 = 32%, F = 6.4, df = 2, 27, p = .005)

Table 4: Coefficients for Quadratic Regression

	(Unstandardized Coefficients)				
	B	Std. Error	Beta (Standardized Co-efficents)	t	Sig.
(Constant)	60.5	3.6		16.1	.00
SCHFI Self-Care Confidence Centered Around 65	0.8	.21	.07	.40	.69
SCHFI Self-Care Confidence Centered Around 65, squared	0.6	.02	.54	3.2	.00

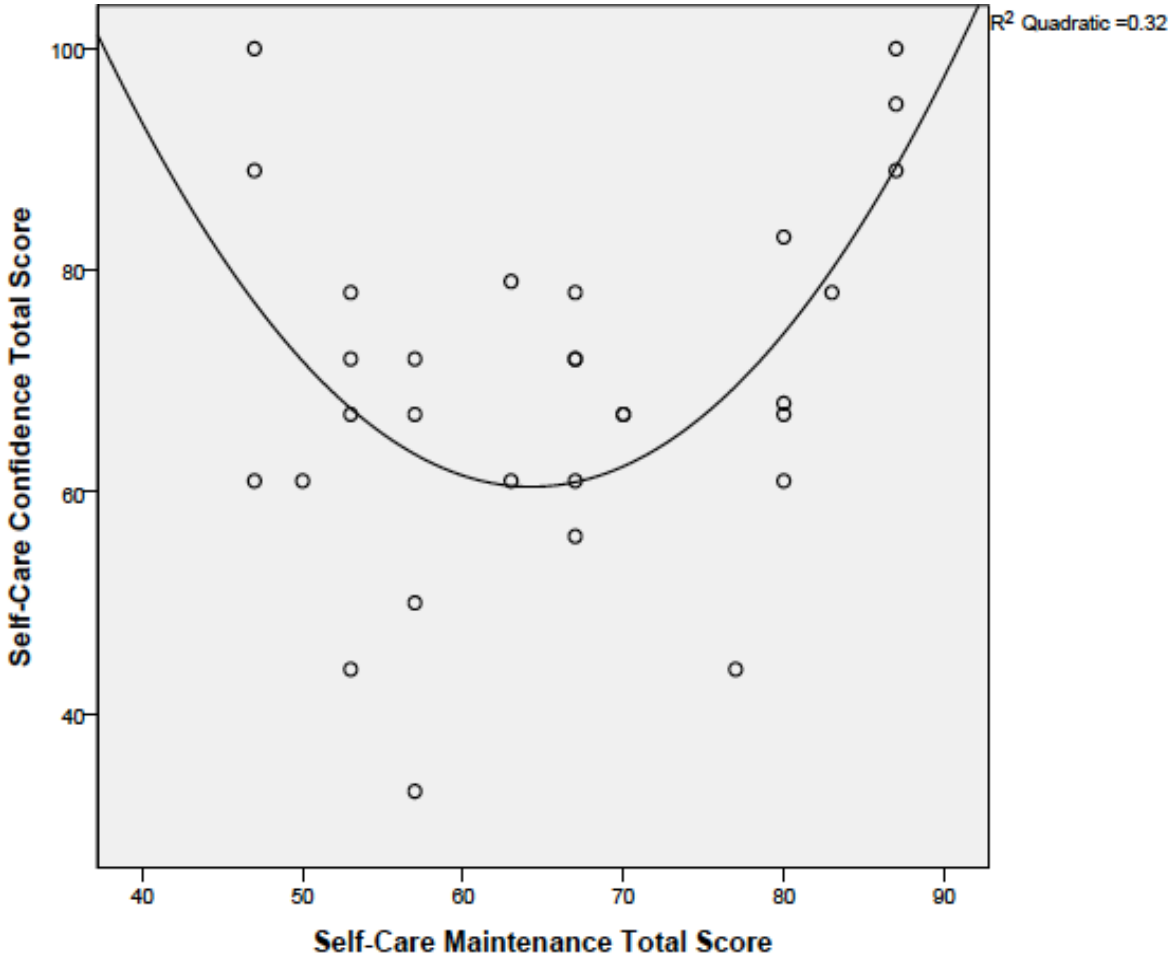


Figure 5: Quadratic Regression Model

This quadratic model displayed in Figure 5 defines the significant and non-linear relationship between heart failure self-care maintenance and confidence. For the quadratic analysis, the data outlier (SCHFI score = 17) was removed as to not bias the regression analysis through extreme leverage and influence.

The parabolic relationship implies that there may be a complex relationship between self-care maintenance and self-care confidence. There may also be three groups within this sample:

(1) those who score inadequately on the heart failure self-care maintenance scale but adequately (≥ 70) on the self-care confidence scale, (2) those who score in the mid-range on the SCHFI for self-care maintenance and who have less than adequate (≤ 69) self-care confidence and (3) those who score adequately on the self-care maintenance scale and adequately on the self-care confidence scale.

Qualitative Results

A total of 24 qualitative interviews (14 inadequate and 10 adequate) were conducted before reaching data saturation Of the qualitative sample, 14 participants scored inadequately on the SCHFI (score ≤ 69) and 10 scored adequately (score ≥ 70). All interviews, including those that were completed in person (n = 8) or via telephone (n= 16), were audio recorded and transcribed verbatim by the primary researcher. Transcripts were reviewed multiple times during the research process to ensure complete understanding of the participant's experiences. Methodological rigor was upheld through an ongoing audit trail and intermittent debriefing with colleagues and experts in the field of heart failure and research methodology. Interview transcripts were first divided into the participant's group which reflected their self-care maintenance score obtained from SCHFI interview data. Comments were then coded into two mutually exclusive and exhaustive categories, positive statements about heart failure self-care (Table 5) and negative statements of heart failure self-care (Table 7).

Table 5: Statements on heart failure self-care in participants scoring inadequately (≤ 69)

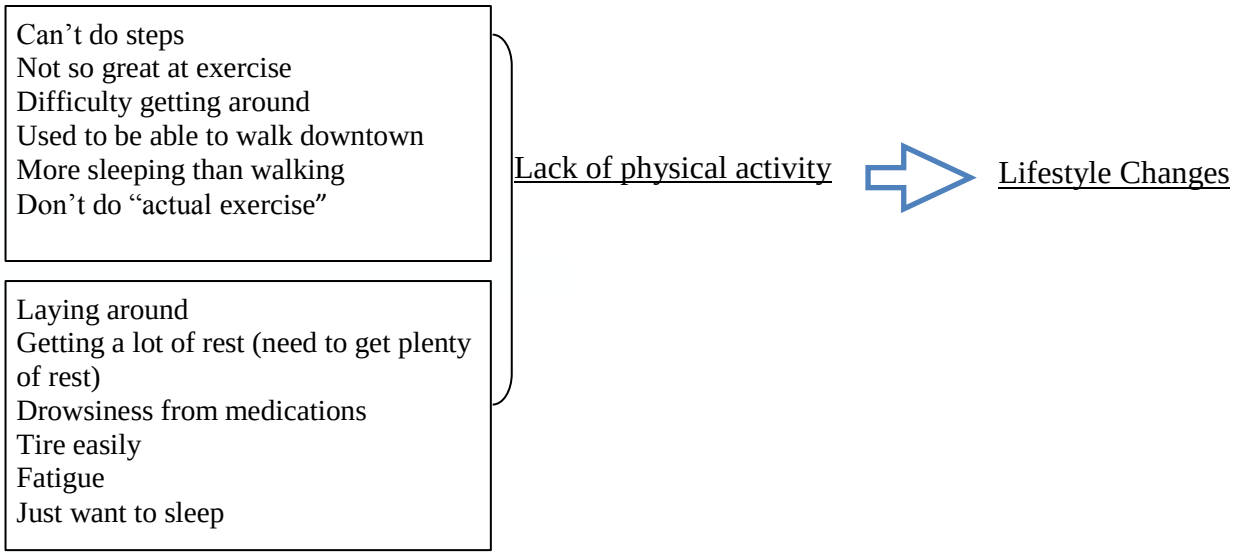
Statement	Positive Statements	Negative Statements
"I take my medicines"	✔	
"The visiting nurse helps me a lot…"	✔	
"…medications make me drowsy."		✔
"…its difficult - the lifestyle changes."		✔

Table 6: Statements on heart failure self-care in participants scoring adequately (≥ 70)

Statement	Positive Statements	Negative Statements
"…Grandkids. I want to see them grow up. I want time with them."	✔	
"I started aerobics…I love to walk"	✔	
"I don't weigh myself at all…the doctor tells me to weigh myself every day and I don't do it."		✔
"I had to stay indoors, I was so short of breath."		✔

Categories with similar content were then clustered in dendrograms, allowing for identification of central themes and the frequency of their occurrence. Selected examples of clustering and formation of dendrograms are displayed in Table 7.

Table 7: Inadequate scores (< 69) Example of Negative Cluster Dendrogram



Qualitative data were supported using direct, meaningful quotes from the participants. An audit trail including the date and time the participant was interviewed was kept by the researcher for further validity of the results. When required, the researcher sought expert opinion from those familiar with the methods of Krippendorff's (2013) qualitative analysis for further validation of results.

Research Question 3: Results

What are the different factors that can be identified which facilitate or impede heart failure self-care behaviors in women scoring adequately or inadequately on the SCHFI?

Research question 3 sought to understand the different factors which facilitate or impede heart failure self-care maintenance behaviors in women scoring both adequately and inadequately on the SCHFI. Participants in the study responded to three open ended interview questions which pursued the understanding their daily heart failure practices. Through the participant narratives of their daily self-care behaviors, positive and negative statements were extracted and coded into the two defined categories: (1) factors that facilitate self-care

maintenance behaviors and (2) factors that impede self-care maintenance behaviors. Factors were then grouped into like categories through the generation of dendrograms. The dendrograms were used to identify common themes across the interview transcripts (Krippendorff, 2013). Transcripts were ultimately compared and contrasted to identify the positive and negative factors which influence of heart failure self-care maintenance behaviors.

There were common themes across the interview transcripts for both facilitating and impeding behaviors. Within the themes, two distinct groups emerged: those taking an active role in their self-care and those adopting a more passive role. Evidence of an active or a passive role was reflected through statements in the qualitative narrative. SCHFI self-care maintenance scores are presented in brackets following the narrative quotation throughout the presentation of results to provide context.

Factors That Facilitate Self-Care Maintenance Behaviors

Three themes were identified that described the factors that seemed to facilitate self-care behaviors in patients scoring both adequately and inadequately on the SCHFI. The themes are: (1) Every day and Always: The importance of routine and compliancy with treatments, (2) Strong Connections: Relationships with healthcare providers, and (3) In Tune: Certainty in heart failure self-care behaviors.

Every Day and Always: The Importance of Routine and Compliancy

A common theme that emerged through both those scoring adequately and those scoring inadequately was routine and compliancy. Throughout the interviews, women noted adherence to the recommended heart failure therapies, specifically to medication regimens. Seventeen of the interviews mention adherence to medication routines. Many women placed great importance and reliance on pharmacologic treatments and often attached a statement of compliance to their

medication schedule. Women described their daily heart failure activities with a sense of a regimental routine. Those women that tended to score inadequately seemed to take more of a passive role in their heart failure self-care behaviors. In the following examples, two participants, both with inadequate self-care maintenance scores, explained performing their routine behaviors with a sense of passivity:

> *"*Well, I take my medicine like I'm supposed to,*"* [57]
>
> *"*Every day I take my medicine- morning, noon and night. Always the pills. I have a box that tells me when to take them*."* [70]
>
> "I take my medicine all the time. I got this little pill box that my daughter made me buy" [47].

In the first quotation, the woman explained she takes her medicine as she's "supposed to," while the other participants expressed the reliance on pillboxes. This passive role in self-care demonstrates the dependence on reminder systems or the act of doing what is prescribed, perhaps without the true knowledge of why the participant is prescribed the treatment or medication. A passive role was again reflected through the statement, "I don't do nothing you're not supposed to do…I don't eat nothing I'm not supposed to eat..." [63].

Similarly, participants scoring inadequately recognized the use of a telemonitoring device as a part of their daily self-care maintenance behaviors. Telemonitoring has a strong presence in the body of heart failure literature as strong contributor to self-care and self-monitoring practices. Use of a telemonitor allows a patient with heart failure to gather biometric data such as heart rate, blood pressure and oxygen saturation and remotely communicate it to their healthcare provider. Use of these monitoring devices was mentioned frequently and seemed to provide a sense of security and reassurance. Participants adopted a passive role in regards to the

telemonitor and depended on the healthcare providers watching the data, rather than relying on their own sense of body awareness. One participant demonstrated the use of the monitor to the researcher during the interview and stated,

> Well, number one, I get up and I do my monitor. Take my meds. This monitor here, I press it and it tells me what to do. It asks me questions, I answer it. I do this every morning. If something comes up that's wrong, they call me. They're always watching me. It's reassuring [67].

Those participants who adopted a more active role in their heart failure self-care maintenance behaviors, spoke about with a sense of knowledge and in a tone that reflected confidence and reassurance in themselves. When asked to describe her daily heart failure care, one participant replied in a very matter-of-fact tone and stated,

> So what do you want to know? I take my medicine. I keep my appointments. My health is very important to me. I walk every day. I do my exercises. I eat properly. Right? I follow my diet and I see the doctor. I don't know what else. That pretty much covers everything. [80]

In this example, this participant who scored adequately [80] did not question the lifestyle she had adopted and was able to quickly and correctly identify the self-care behaviors that kept her in her good health. In addition to reporting strong adherence and compliance with medication treatments, women frequently reported seeing their healthcare provider on a regular basis and keeping their appointments. Women who exhibited an active role in adhering to treatments not only were able to correctly identify the treatments, but provided strong and specific examples. "My diet changed when I was diagnosed. I don't eat a lot of cholesterol things like cheese or eggs, bacon…I watch my fluid intake" [80] and "I eat a lot of greens, a lot of baked chicken and um, a lot of fruits," [77]. This is in contrast to the participants assuming a more passive role that identified a change in their diet but did not mention specific foods to avoid.

Strong Connections: Relationships with Health Care Provider

The idea of a strong connection with a health care provider was prominent across the interview transcripts. Although the interview questions did not specifically address any provider relationships, participants openly spoke of meeting with doctors, nurses or aides as a part of their daily self-care maintenance behaviors. This facilitating factor was notable in the participants scoring both adequately and inadequately; however, the characteristics of the relationship differed between participants assuming an active verses a passive role in their heart failure self-care.

Participants scoring less than or equal to 69 more often mentioned a provider in some way throughout the interview compared to the participants scoring adequately. These inadequately scoring participants adopted a passive role in their self-care and exhibited a strong reliance on the advice and guidance of their healthcare provider. Two women mentioned their provider by name and others expressed their reliance on a provider through statements such as, *"*The visiting nurse helps me a lot. She puts my medicine in the box, seven days" [63] and "I have a nurse that comes and they do my medicine and they give me advice and tips on what to do." [57]

A participant with a similar SCHFI score [63] alluded to a telemonioring device, "The visiting nurse came yesterday and they, um, they put a something like a scale and I could get my blood pressure. They put the machine back so I could get everything." Use of a telemonitor was not specifically addressed during the interview process but many patients felt inclined to mention it as a source of safety, support, and a part of their routine self-care maintenance behaviors.

Women scoring adequately also expressed a relationship with their healthcare provider. These participants spoke of their healthcare provider as a collaborative relationship, rather than

in a sense of dependency. This joint relationship with a healthcare provider embodies the active role in heart failure self-care. One participant stated, "I understand what my doctors tell me and I know how to react to their advice" [87]. This participant exemplifies a collaborative rather than a dependent relationship. She specifically mentions reacting to the advice from doctors, rather than adopting recommendations without a full understanding of the prescribed treatments. Assuming an active role in a relationship with a caregiver seems to positively influence heart failure self-care behaviors through the understanding of the recommended treatments. Participants assuming the active role in self-care understood the "why" of the treatment and not just the passive "what" treatment in which to adhere.

"In Tune" and the Certainty of Heart Failure Self-Care Behaviors

Certainty and confidence in self-care maintenance behaviors underlie the Situation Specific Theory of Heart Failure Self-Care (Figure 1). This self-confidence was prominent throughout the qualitative interviews. Interestingly, it was the participants scoring inadequately that most often mentioned their self-confidence in their self-care maintenance performance, as if those participants who scored inadequately felt as if they had to subconsciously validate their self-care behaviors. In some instances, self-care maintenance scores were poor, yet the participant responded with statements that alluded to self-care confidence. One participant cited her years of experience with the syndrome stating, "I've been dealing with it for fourteen years so I'm pretty strong," [57]. That same participant referenced her perceived overall good health in saying, "I haven't had any complications for awhile," [57].

Striving to feel in good health and avoid complications was reflected in numerous interviews. One participant spoke about the struggle to adhere to the recommended treatments and self-care maintenance behaviors to alleviate the associated feelings of anxiety. She stated,

> So I'm trying but I do what I can do because otherwise, it's on your mind…Sometimes you know like, sometimes it comes to your mind. A lot of things come to your mind, suicide, something like that. But um, it doesn't come to my mind you know, I gotta keep going [63].

Confidence in holding personal health as a high regard was reflected in a woman scoring less than adequate on the SCHFI. Although she had a low score, her statement of, "My health is important to me," [47] demonstrates the strong role her personal health and wellness plays in her life. Echoing the importance of personal health was a statement made by a close friend and caregiver of a participant with an inadequate score. Adjusting and adopting new behaviors to feel confident in heart failure self-care was evident when the caregiver stated, "We're making these habits. She [the participant] is very in tune with herself and her body with recognizing the warning signs," [67]. Interestingly, these statements of confidence in body awareness came from the participant's caregiver and not the participant herself. The close involvement of a family friend in the participant's heart failure self-care is another example of a participant with a low scoring self-care maintenance scale and a passive role in heart failure self-care. Holding certainty in recognizing the warning signs and symptoms of heart failure is a facilitator of heart failure self-care practices.

Body awareness and an active role in the certainty of heart failure self-care were reflected in participants scoring adequately on the SCHFI. Participants seemed to rely on their own assessment of their physiological baseline. Sometimes, participants stated not adhering to prescribed medical treatments citing their own self-assessment and awareness as more meaningful. One participant stated,

> And I do what I'm supposed to do…I don't weigh myself at all. And I know the doctor tells me to weigh myself every day and I don't do it. I have a scale in my house. I know why I need to do it but I know when I'm retaining fluids- my rings don't come off [87].

This participant openly admitted her non-compliance with obtaining the recommended daily weight but also provided an alternative to relying on a piece of biometric data. Another participant exemplified an active self-care role in her certainty of behaviors through the statement, “Here they serve you breakfast- a cereal I don’t eat because it is too salty” [87]. This woman was living in a homeless shelter at the time of her interview and was still able to confidently choose the correct foods to eat. Later in the interview, she stated, “I’m good with taking care of myself.” Her statements of confidence reflected her active role in her own heart failure self-care behaviors.

Factors That Impede Self-Care Maintenance Behaviors

Three factors that seemed to impede self-care behaviors in patients scoring both adequately and inadequately were identified: (1) “I don’t seem to have a problem:” Denial and Misunderstanding, (2) “It’s very frustrating:” Changes to lifestyle, and (3) “I’m juggling a lot right now:” Managing co-morbidities. Active and passive roles in heart failure self-care were again observed throughout the interview transcripts.

“I don’t seem to have a problem.” - Denial and Misunderstanding

There was an apparent knowledge deficit that seemed to impede self-care maintenance behaviors. This knowledge deficit related to heart failure self-care was reflected in the statements of women scoring inadequately on the SCHFI: “Maybe it’ll heal itself, you know? I’ll be in remission or something,” [57] and “I don’t seem to have a problem,” [47]. Symptoms directly related to a heart failure exacerbation were not recognized by some participants. For example, two different participants, one scoring adequately and one scoring inadequately, failed to correlate swollen ankles and water retention with their chronic syndrome. “My ankles swell

sometimes. My ankles and my feet, too. I don't know why that happens," [47]. This statement reflects the passive self-care behaviors observed in those participants scoring inadequately. Statements of misunderstanding were not presented in a way to seek additional information regarding the diagnoses and symptomatology, yet in a way of acceptance and loss of control.

Maintaining an adequate fluid balance was another source of denial and misunderstanding. A woman with an inadequate SCHFI score stated, "Once in awhile, I might have a bottle of water but I don't do it on a daily basis, you know what I'm saying? I'll drink coffee more than I drink water," [53]. Although she denied having a high water intake, she admitted to drinking generous amounts of coffee but seemingly failed to equate the two as contributing to her overall liquid intake. Similarly, another participant with an inadequate score struggled with fluid intake. She stated, "I try to watch what I drink but it has been so hot lately, I need water or juice. I try to not drink sodas but I guess soda is better than nothing. Is it?" [67] This misunderstanding and inability to understand recommendations of fluid intake in participants inadequately may have a negative effect on overall heart failure self-care.

Misunderstanding and denial was again seen when the participants spoke about the necessity of obtaining a daily weight. One participant seemed to equate her weight with her actual body mass and not fluctuations in fluid due to her chronic heart failure. She stated, "The hospital gave me a scale to weigh myself but I forget a lot. I need to get better at that but the number doesn't change much," [67]. Equating the number on the scale as being related to fluid retention due to heart failure as opposed to body mass may cue this participant into measuring her weight on a daily basis.

In women scoring both adequately and inadequately, denial and contradictory behavior was apparent. A woman scoring inadequately stated, "I know what I need to do but sometimes I

just can't do it," [53]. Assuming a passive role in heart failure self-care and admitting defeat rather than troubleshooting may have contributed to this participant's low self-care maintenance score.

This same participant admitted to continuing with behaviors that may impede her chronic condition, "I've been cutting down on my smoking. I still love having my coffee and cigarettes but I've cut it down to 2-3 a day," [87]. This participant recognized the detrimental behavior, yet seemed to equate cutting down with the same benefit as the complete cessation of smoking. Although she may be exhibiting misunderstanding through continuing to smoke, she is taking an active role in her heart failure self-care by working to eliminate tobacco consumption.

"It's very frustrating." - Changes to Lifestyle

Women scoring both adequately and inadequately on the SCHFI mentioned the lifestyle changes that they had to cope with directly related to their heart failure diagnosis. Many participants mentioned the changes in diet and activity levels. A participant scoring inadequately cited her decreased activity tolerance as a barrier to eating a well-balanced and recommended diet. She stated, "I get tired standing at the stove to cook so I really don't cook that often. I eat leftovers or whatever my son brings me. I'm not very hungry most of the time," [53]. Similar to the other themes, this low scoring participant indirectly adopted a passive role in her heart failure self-care through the reliance on her son to bring her food.

Passive roles in self-care were again seen when speaking about dietary restriction of sodium. A caretaker of a patient stated, "She has a taste for salt and we've definitely taken that away because of the swelling in the feet and it's just not good for her," [67]. This participant did not make the active and engaged decision to eliminate her own sodium but relied on her caregiver to do so.

Dietary changes also affected those women scoring adequately on the SCHFI: A woman who scored adequately cited her dietary changes but also spoke about the active role both her and her husband adopted to better manage their chronic conditions. She reflected on the dietary changes they made together when she stated, "I can't cook. I can't use the stove so my husband usually gives me some breakfast. We don't use salt. My husband, he has high blood pressure, so he has to watch what he's doing too. We've been doing this for some years," [83].

There were different levels of activity tolerance across the participants. In this case, there seemed to be distinct differences in women scoring adequately versus those scoring inadequately. A woman with a high SCHFI stated, "I'm okay to move around the house and all but when it comes to like, doing much in the way of harder stuff, I have to take my time," [83]. This statement is a stark contrast from participants scoring inadequately who seemed to have to cope with more difficult changes, such as a complete relocation. "We don't usually live here, we usually live in another space but we have to do the steps and I can't do that," [63] and overtly stating, "It's difficult- the lifestyle changes," [67]. Descriptions of major declines in activity levels were seen through a participant reflecting on her previous level of activity tolerance, "I used to be able to walk downtown, of course, I was younger too, but not anymore," [53]. Changes in activity levels were also present in women scoring adequately on the SCHFI. One participant stated, "As being a very active person in the past, I used to walk, I used to run, I used to ski and it's very frustrating not being able to do anything. I live on the second floor; I need help leaving my own house. I can't see, I can't carry the oxygen. It's very frustrating," [83].

Balancing rest and work was a lifestyle change that seemed to negatively affect heart failure self-care behaviors. Although increased rest and decreased stress on the myocardium was originally suggested for heart failure patients, exercise is now recommended for heart failure

patients and has been shown to improve both systolic and diastolic function as well as to increase quality of life and decrease heart failure related hospitalizations (Gielen, Laughlin, O' Conner & Duncker, 2015). Participants scoring inadequately and adequately struggled with maintaining recommended physical activity habits.

Participants assumed both active and passive roles in regards to physical activity. Participants cited difficulties in breathing, "I take myself on a half an hour walk which would normally help me, but then again, as I walk, my breathing starts messing with me," [77]. Rehabilitation practices were also a source of difficulty: "When I first got diagnosed, I had to re-learn how to walk; I had to re-learn how to use the stairs. I was so weak for so long. It was a challenge," [70]." The need for frequent rest was also expressed: "I do more sleeping than I do walking these days but I think that's okay. The doctor told me my heart needs to rest," [67]. The language used to describe the participants physical activity ("I take myself…) reflects the active role in heart failure self-care. In contrast, the participant with the inadequate score cited her doctor's recommendations as the reason for her increased rest.

"I'm juggling a lot right now." - Managing Co-Morbidities

Patients diagnosed with heart failure often manage more than one chronic condition. This is reflected in both the scientific literature and through the qualitative interviews conducted with participants of this study. Co-morbid conditions affected participants scoring both adequately and inadequately on the SCHFI. Active and passive roles were again seen throughout the theme of managing co-morbidities. This impeding factor was reflected through statements such as, "I'm juggling a lot right now," [67] and references to specific conditions such as, "I got diabetes too and I'm trying to correct that," [87]. Although these two statements do not overtly refer to an active or a passive role, the language used by the participants to describe their conditions self-

reflects the role in which they assume. The participant scoring inadequately admits to juggling a lot and carries an aura of being overwhelmed while the adequately scoring participant uses strong statements. These strong statements are seen through the use of the word "I" and the participant taking full ownership and responsibility of their condition.

Participants cited the need to make multiple lifestyle changes to adapt and manage various chronic conditions. One adequately scoring participant stated, "My kidney disease is getting worse and I'm especially watching foods- trying to have no, um, light on the foods with phosphates," [83]. The active role in heart failure self-care is exemplified through the ownership of self-care maintenance behaviors and reflected through the high self-care maintenance score.

Maintaining a healthy weight is important to overall health. One adequately scoring participant made the connection between a healthy weight and her breathing pattern, again exemplifying an active self-care role. "I've hooked up with a nutritionist and I watch my weight- I don't want to gain weight because that makes it even harder to breathe," [87]. Because many heart failure patients manage multiple chronic conditions, utilizing resources such as a nutritionist to balance more than one therapeutic diet may be beneficial.

Research Question 4: Results

What are the motivating factors that influence heart failure self-care behaviors in women that score adequately and inadequately on the SCHFI?

Understanding the motivating behaviors behind the self-care maintenance behaviors of women was the goal of research question 4. Participants were asked to respond to an open ended question regarding their motivation behind caring for themselves with a diagnosis of heart failure.

"I want more time with them"- The Influence of Family and Friends

Eighteen of the twenty-four transcripts mentioned the role and influence of family and/or friends. Various family members including spouses, children, and grandchildren were frequently mentioned along with the desire to live to experience important life events. One woman [57], who was previously incarcerated, specifically addressed hope for the future,

> My son, he worries about me a lot…And you know, I just try to do what I need to do, you know, so that I can live longer and be here for him, you know. He's only 20, so, you know, I want to see him get married.

Women that participated in this study were of a wide age range and similarly had children of a wide age range. While some women spoke of grandchildren or great-grandchildren, another woman cited her young son motivation to live, "My son motivates me. He's 12, he's my only son. He's my inspiration and he's the reason why I'm still here," [70].

The influence of grandchildren was very evident across interview transcripts. Many women cited their grandchildren as their sole motivation to live and experience their life milestones. Participants made statements such as, "I have grandchildren- two of my sisters have great grandchildren and I want to be like them. That idea of the great grandchildren motivates me," [77] and "My grandchildren motivate me. They're everything to me, they're my life. They really keep me going," [80]. For many women, it was the motivation to live and perform heart failure self-care behaviors to extend life and continue to experience the presence of grandchildren. One woman became emotional while expressing her love for her grandchildren,

> I got a beautiful six year old granddaughter to live for. That's what motivates me. Her and my children are what I live for. You know what I mean? They're- you know, my husband is gone. They're all I live for. That's what motivates me (laughs) you almost have me in tears!

In an interview conducted with both the participant and the caregiver of the participant [67], social influences were again prominent. While describing the participant's relationships, the caregiver stated, "She wants to be home and enjoy, you know, what little time she has with her husband….very involved in the community…she has family that is always around." This participant continued to remain active in community centers and churches despite a heart failure diagnosis and recovering from a recent stroke. The caregiver that participated in the interview had been a friend of the participant for many years and her desire to participate in the interview supported the strong influence of not just family members, but the support of strong friendships as well.

Friendships were a strong factor on another woman's [87] self-care behaviors when she spoke of the support she found through her close friends,

> I do my exercises with my friends- we'll have a couple of people come to the house and I think they started for me but they won't say so! (laughs)…I don't have family, but I have a lot of friends. I was just talking to one before I came in. Like, I told her, I went to Dunkin Donuts and she says, "See! We tell you not to go there and you go ahead and do it anyway. She gets- like when she talks to me, she says, why didn't you go to Dunkin Donuts and get your coffee and then call me?" She doesn't like to hear what I order. I think she feels responsible to keep me in check. I have a lot of help.

In the cases where family members were not always around or did not live in the state, their influence was still a strong positive factor. One participant [53] spoke of the strong influence of her out-of-state children,

> They're not- you know, my kids, they don't live in the same state that I do. One lives in Maryland, one lives in Virginia. You know, and they're not here…I see what my kids are going through with me. I remember when my mother was sick but I was of a different generation. I didn't say some things to my mother that my kids say to me. I feel like I'm blessed because of the accomplishments my children have made and I have this little granddaughter…I have a beautiful home. My family is important to me. That's what keeps me alive, you know. My family. I couldn't ask for anything more.

While most participants spoke of their family and friends in a positive light, one participant [57] recognized the difficulty with being separated from loved ones, "I don't get to see my friends or family too often anymore so that's tough sometimes." Another participant [63] found motivation in older family members such as her mother. She stated,

> I got to keep going. And I'm going to keep going. I got my family. I got my mother, and she-you could see, she's not slowing down. No! The only thing she got is arthritis. She's 97. She goes to the supermarket herself…I hope I'm like her when I'm 97.

"I'm not ready"

Living life and the continued life experiences was a sole motivating behavior for many women. Women scoring both adequately and inadequately often did not cite one particular source of motivation, rather citing life in general and the idea of not being ready to give up on life. While it is known that a diagnosis of heart failure is often fatal within a few years of diagnosis, the motivation to live and continue to experience life in general was present in the qualitative interviews. One woman recognized her chronic condition but also recognized her ability to interact with others. She stated,

> I'm not ready to give up! I get by, slowly and maybe not like I used to, but I get by. I look forward to going to church, seeing my friends. They have a lot of grandchildren and I don't but I still like hearing their stories. I'm still able to see and hear these things! My bad heart doesn't affect my hearing. Things have changed but I'm getting used to it. I just need a lot of help. [67]

Although her score was less than adequate, one woman expressed her motivation through the importance of health over being wealthy. "Health to me is important 'cause you know, if you ain't got it- you can have all the money in the world but if you don't got your health, what's that got to do with you?" [53]. Remaining in a state of perceived health and wellness was also reflected when a caregiver who participated in the qualitative interview saw the motivation in her

friend with heart failure. Although the participant required a lot of assistance to manage her chronic condition, her caregiver observed, “She’s very motivated to be independent,” [67]

Some women answered the interview question with a simplicity that reflected the love and desire to continue to live a full and quality life. These participants did not go into lengthy descriptions of their friends, family or motivators to live but simply expressed their desire to live. through statements such as, “I don’t understand. I just to live,” [80], “What influences me? I want to be in the best shape I can,” [80] and “Life in general keeps me going…My motivation? I just want to be alive,” [87].

Part III: Mixed Methods Results

In what ways do the interview data that investigate self-care in women with heart failure help to explain the quantitative results about self-care maintenance and the influence of self-care confidence in both those scoring adequately and inadequately on the SCHFI?

Following the analysis of the quantitative and qualitative data, the two strands were then combined to generate the mixed methods results. The goal of research question 5 was to use the qualitative transcripts to validate and further evaluate the results from the quantitative data.

As reported through research question two, there was no statistical significance found through the linear correlation of self-care maintenance and self-care confidence scores in this population . This quantitative finding seemed to be supported through the statements made from women scoring both adequately and inadequately on the SCHFI. Women scoring inadequately adopted a more passive role in heart failure self-care and often made statements that either directly or indirectly referred to their self-care confidence and their ability to manage their condition. This was most often seen through the “Misunderstanding” theme and through

statements such as, “I don’t seem to have a problem,” [47] or “I try to take care of myself…I think I do pretty good, you know,” [57].

As evidenced by the quadratic regression, these statements reflect the group of participants with inadequate self-care maintenance and high self-care confidence. The three groups generated from the quadratic regression equation are depicted in Figure 6.

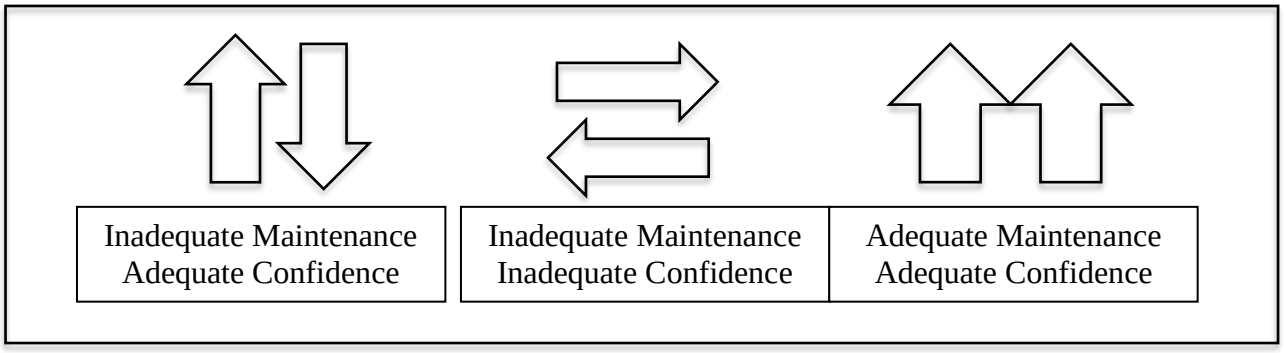


Figure 6: Display of three groups generated from Quadratic Regression

The average length of heart failure diagnosis was 5.33 years with a range of 0 to 20 years. Heart failure has a high rate of mortality, especially after a 5 year diagnosis. A histogram displaying the distribution of the length of heart failure diagnosis is displayed in Figure 7. This histogram visually represents a population coping with heart failure as a newer diagnosis. Heart failure knowledge was not measured in this study, yet a lack of interactions with a healthcare provider may lead to lower self-care maintenance scores and consequently, ignorance to correct heart failure self-care maintenance behaviors. This newness of diagnosis may not be reflected physiologically or through disruptions in their normal level of activity, leading to higher confidence levels and the perception of good health.

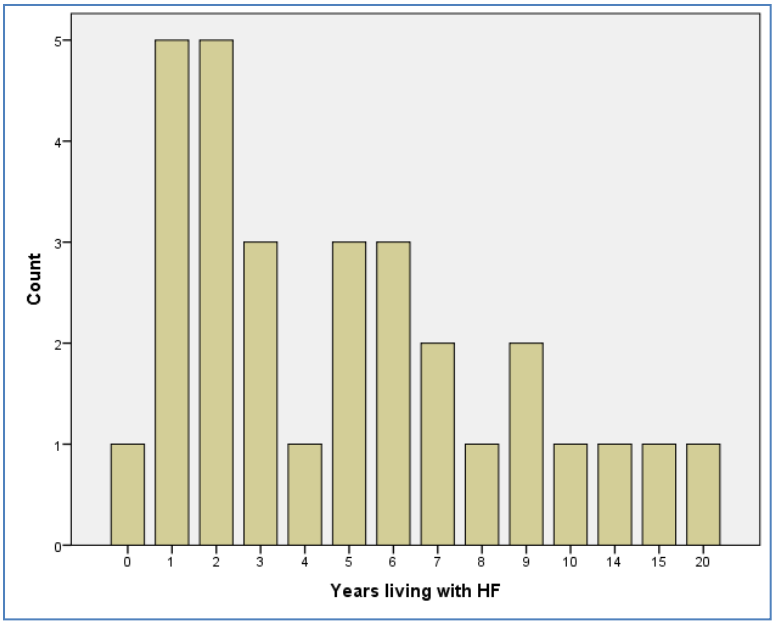


Figure 7: Histogram of years living with heart failure

Summary

This chapter presented the quantitative, qualitative and mixed methods results from the study. Descriptive statistics evaluating the demographic profile of the participants, Pearson's correlation and quadratic regression analyses along with the content analysis of qualitative findings were considered. Mixed methods results were also presented.

Comparison of the study's findings to current nursing research is presented in chapter 5. Strengths, limitations and implications for further research, practice and nursing education are also offered.

Chapter 5: Discussion

Introduction

This concluding chapter presents a summary of both the study and its findings. A discussion of pertinent findings and connections to current literature and practice will be made. Limitations will be reviewed. Finally, implications for nursing education, research, and practice will be presented.

Summary of Study

This convergent mixed methods study aimed to explore the facilitating and impeding factors women with heart failure face while performing daily recommended heart failure self-care behaviors. This study focused solely on women because women are disproportionately understudied in the heart failure literature. Although approximately 47% of all individuals diagnosed with heart failure are female, the mean percentage of women participating in large scale or clinical studies is 31.7% (Pressler, 2016). Findings from these studies are generalized to both genders even though it has been proven that there are distinct gender differences, specifically in heart failure self-care (Dickson et al., 2011). The convergent mixed methods design allowed for the researcher to generate new knowledge through the collection and analysis of both quantitative and qualitative data. The following research questions guided the present study:

Quantitative*:*

1. What is the distribution of self-care maintenance in women with heart failure?
2. Is there a correlation between high and low scores of heart failure self-care maintenance and high and low scores in heart failure self-care confidence?

Qualitative*:*

1. What are the different factors that can be identified which facilitate or impede heart failure self-care behaviors in women scoring adequately and inadequately on the SCHFI?
2. What are the motivating factors that influence heart failure self-care behaviors in women that score adequately and inadequately on the SCHFI?

Mixed Methods*:*

1. In what ways do the interview data that investigate self-care in women with heart failure help to explain the quantitative results about self-care maintenance and the influence of self-care confidence in both those scoring adequately and those scoring inadequately as reported on the SCHFI?

Discussion of Findings

Quantitative

Sample

Participants in this study predominately identified themselves as Black (75%) and were mostly unemployed (77%), unwed (single, divorced or widowed) (86%), with a high school education (74%) and living with someone else (68%). The demographic profile was further broken down into participants that scored adequately versus those that scored inadequately in heart failure self-care (Table 3). Descriptive statistics and independent sample t-tests were performed. There were no statistically significant differences between the demographics of each group.

Research Question One

The mean score on the self-care maintenance scale of the SCHFI was 61.1 with scores ranging from 17-87. Higher scores on the SCHFI reflect better self-care practices with adequate self-care being defined as a score of 70 or greater (Riegel et al., 2009). The average self-care maintenance score for this sample (61.1) was similar to other heart failure self-care studies that used similar research methods. A study investigating gender differences in heart failure self-care had a total self-care maintenance score of 72.7 (Dickson et al., 2011). Chronbach's alpha (α) for the maintenance (.66) and confidence (.78) subscales in this study were similar to previously reported values (Riegel et al., 2009).

A higher percentage of participants with an adequate self-care maintenance score lived alone (45.5% compared to 25%). This may reflect more adequate scoring participants assuming an active role in their heart failure self-care because they did not have a constant source of in-home support on whom to rely. Although social support has been shown to improve heart failure self-care scores, this may also contribute to the passive role that many of the inadequately scoring participants assumed. Having another individual in physical close proximity may lead to dependency on others rather than relying one's own self-assessment. The effect of being married on heart failure self-care has conflicting results throughout the available literature (Lee et al., 2009; Riegel et al., 2010).

Research Question 2

Analysis revealed a weak, positive correlative relationship between heart failure self-care maintenance and self-care confidence in this sample (r = .192). This value was not statistically significant (p = .301). Statistical significance may have been lost due to the under-powering of the study. Previously conducted studies have demonstrated that self-care confidence is a

mediator of self-care maintenance behaviors (Cené et al., 2013) as well as an association between higher self-care confidence and better heart failure management (Heo et al, 2008). Mediation analysis on the SCHFI was performed through a series of structural equation models and self-care maintenance was found to be a mediating variable between self-care confidence and heart failure self-care management (Vellone, Pancani, Greco, Steca, & Riegel, 2016). In addition, higher levels of heart failure self-care maintenance were found to be associated with higher quality of life and lower hospitalization rates related to heart failure (Buck et al., 2015). These findings support the need for a routine assessment of a patient's self-care confidence and their ability to perform heart failure self-care behaviors.

As evidenced by the results of the quadratic regression analysis, high self-care confidence may not be indicative of high self-care maintenance behaviors. While there was a grouping of individuals in this sample that represented adequate scores in both domains, participants also had inadequate scores in both domains and inadequate maintenance with adequate confidence (Figure 6).

A possible explanation for individuals who scored adequately in the self-care confidence domain and inadequately in the self-care maintenance domain may be the role of experience and length of diagnosis. It is known that experience with heart failure symptoms increases self-care confidence (Riegel et al., 2010). This is again supported by the Situation Specific Theory of Heart Failure Self-Care and the notion of Naturalistic Decision Making (NDM). The participants in this study had an average length of diagnosis of 5.33 years. A shorter length of diagnosis may lead to fewer encounters with a health care provider and fewer opportunities for heart failure education. Admission frequency was shown to be a determinant of heart failure self-care

behaviors as more admissions relate to more interactions with healthcare professionals (Tsai et al., 2014).

The role of co-morbidity also seemed to influence the relationship between self-care confidence and self-care maintenance. Previously conducted studies have shown that fewer co-morbid conditions led to a stronger relationship between self-care maintenance and confidence (Buck et al., 2015). Although co-morbidity was not a variable quantitatively measured in this study, participants willingly and openly spoke of their struggles with conditions such as previous strokes, asthma, and kidney disease during the qualitative phase.

The impact of co-morbid conditions was apparent through the qualitative theme "I'm juggling a lot right now." The multiple lifestyle changes that are required to successfully manage common co-morbid conditions such as diabetes or respiratory insufficiency may have a hindrance on one's self-care maintenance and confidence. Coping with multiple co-morbid conditions interferes with a patient's ability to adequately manage their heart failure self-care maintenance behaviors and seems to have a moderating effect between self-care confidence and self-care maintenance (Dickson et al., 2013). Increasing an individual's self-care confidence may in turn increase self-care maintenance behaviors. A call for more interventions to increase self-care confidence in an individual living with heart failure has been made (Vellone et al., 2016).

Qualitative

Research Question 3

Various factors affecting heart failure self-care in positive and negative ways were identified through the collection and analysis of qualitative data. Factors that seemed to positively influence self-care maintenance behaviors included: Routine and compliancy with treatments, relationships with the healthcare provider, and certainty in prescribed behaviors.

Factors that seemed to negatively influence self-care behaviors were identified to be: Denial and misunderstanding, changes to lifestyle, and managing co-morbidities. Across all qualitative transcripts, an underlying notion of participants adopting either an active or a passive role in heart failure self-care emerged. The active and passive roles that emerged from this data was validated by an expert in heart failure self-care and her previous experiences with this population at the conclusion of this study.

According to the American College of Cardiology (2015), women often assumed a passive role in heart failure self-care. This idea has been previously identified in the literature (Riegel et al., 2008). In a mixed methods study, those participants adopting a passive role tended to put more emphasis on their relationship with others, including their health care provider. This method of self-care was more collaborative and the participants held the opinion of others in a high regard (Dickson et al., 2011). This was reflected through the qualitative theme "Strong Connections: Relationships with the Health Care Provider." The strong relationship was seen as a factor which positively influenced self-care, however; further analysis of the theme identifies the importance of the relationship as being more collaborative rather than dependent. Through the words and phrases the participants chose to describe their own heart failure experiences, it is apparent which individuals assumed an active role in their health situation rather than as opposed to a passive role in their heart failure self-care.

An active role in self-care of chronic conditions has been associated with improved outcomes and higher adherence to treatments. It is important for health care providers to identify potential barriers to a patient assuming an active role in their self-care (Gardetto, 2011). Conditions such as depression, decreased activity tolerance, increased fatigue, and lack of support from both the physician and patient's social connections have been identified as barriers

to an active self-care role (Jerant, von Friederichs-Fitzwater, & Moore, 2005). Many of these barriers are common with heart failure patients and should be addressed to promote the patient's assumption of an active role in their heart failure self-care activities.

Research Question 4

There is ample evidence supporting the role of social support and its positive impact on heart failure self-care. Social support came through as the primary motivating behavior for heart failure self-care. Nearly all participants mentioned finding motivation through their nuclear and extended families. Social support has a positive impact on heart failure self-care behaviors and seems to be a strong influence on self-care maintenance behaviors (Graven & Grant, 2014).

Similar to knowledge, health literacy seems to play an important role in self-care. In a correlational, longitudinal study conducted over four months, a positive, longitudinal relationship between health literacy and self-confidence for self-care behaviors was found (Chen et al., 2013). Participants in this study had varying levels of education, (Table 3) reinforcing the need for further investigation into health literacy and its impact on self-care maintenance behaviors.

Heart failure self-care has been broken down into typologies that embraced the importance of social support and that further classified a patient's active or passive role (Buck, Kitko, & Hupcey, 2014). The typologies are either collaborative or complementary. In a collaborative dyad, either the patient and or a caregiver assume the primary responsibility for managing the chronic syndrome. When the patient embraces the responsibility, they are taking an active role in their self-care rather than assuming a passive role and allowing the caregiver to undertake full responsibility. In a collaborative role, there is overlapping responsibility. As the illness progresses, dyads may shift and responsibilities may change depending on the patient's level of independence (Buck et al., 2014).

Many participants in the study cited specific family members and their influence on their heart failure self-care. Participants spoke of adhering to diets along with other family members or relying on close family members to provide a heart failure friendly diet. This is reflected in the current research. A family member's influence was found to be significant in a study testing family partner interventions specifically in the areas of medication adherence ($p = 0.004$) and diet ($p = 0.012$) (Stamp et al., 2016). Familial influences have an impact on both self-care maintenance behaviors and self-care confidence in these behaviors.

Mixed Methods

Research Question 5

The SCHFI defined two groups of individuals: Those who scored adequately (≥ 70) and those who scored inadequately (≤ 69). Investigation through a quadratic analysis has shown there may be an important third group with high self-care confidence despite low self-care maintenance scores. As previously mentioned, this finding may be attributed to a lack of heart failure knowledge related to the time of diagnosis. Considering a patient's role in their heart failure self-care, either active or passive, is also an important aspect when evaluating heart failure self-care behaviors.

Typologies of heart failure were defined in a mixed methods study (Dickson et al., 2008). Patients were classified as experts, novices or inconsistent in their heart failure self-care practices. Those that were classified as experts had the knowledge, skill and self-confidence to perform their self-care behaviors. They performed these behaviors on a consistent basis and had favorable attitudes toward their diagnoses. In contrast, those classified as novices or inconsistent lacked skill and proper management of heart failure symptomatology. Specifically, novices often lacked self-confidence and were observed to wait for an experience to guide any further

knowledge of their condition. Similarly, those classified as inconsistent often did not have a plan to execute when experiencing heart failure related symptoms (Dickson et al., 2008). These classifications embody the two groups of patients assuming an active role (experts) and a passive role (novice, inconsistent).

Participants in this study also fell into three similar categories (Figure 8). The group most similar to Riegel's novice group seemed to be those that were highly confident but poor in their self-care maintenance behaviors. Riegel and colleagues (2008) note that novices in heart failure self-care may not yet feel the symptom burden and feel a greater sense of control because of minimal interruptions in their daily life. Participants who scored inadequately made confident statements such as "I don't seem to have a problem" [SCHFI score 47] and "…I think I do pretty good, you know," [57]. This reflects the nature of the novice or inconsistent typology. These patients are at a high risk for heart failure exacerbation and clinicians should focus on developing interventions to advancing the novice/inconsistent patient into an expert classification.

The parabolic relationship between self-care maintenance and self-care confidence that was discovered through this study solidifies the importance in categorizing heart failure patients as novice, inconsistent, or expert (Figure 8). It was previously determined that novices tend to have low self-confidence while experts are highly self-confident. Individuals deemed inconsistent have high self-confidence but their daily activities do not seem to be impacted (Riegel et al., 2011). The sample of this study supported these previous findings.

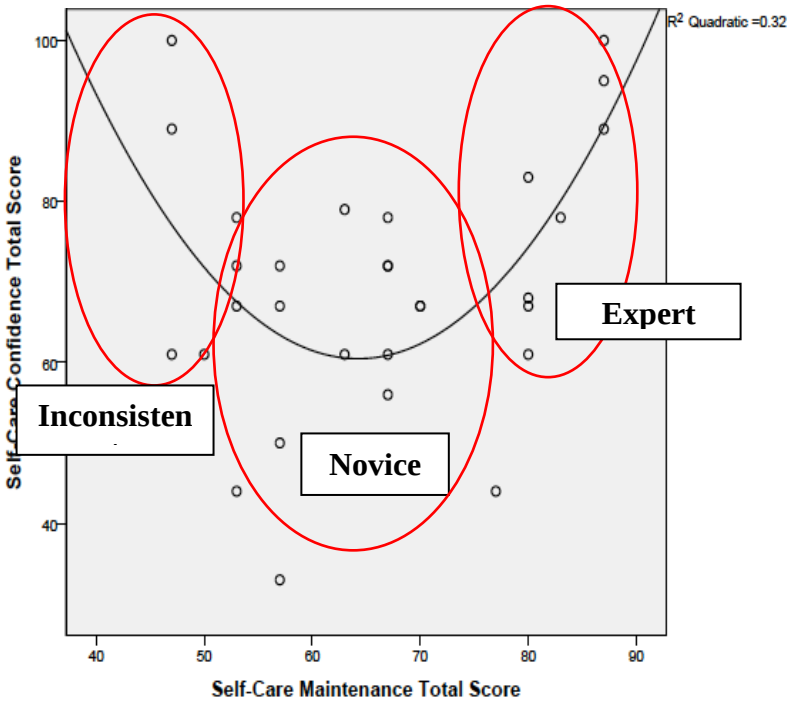


Figure 8: Typologies of Heart Failure Self-Care

Integrating this new, parabolic relationship into the previously discovered body of literature further defines and supports the three typologies of heart failure.

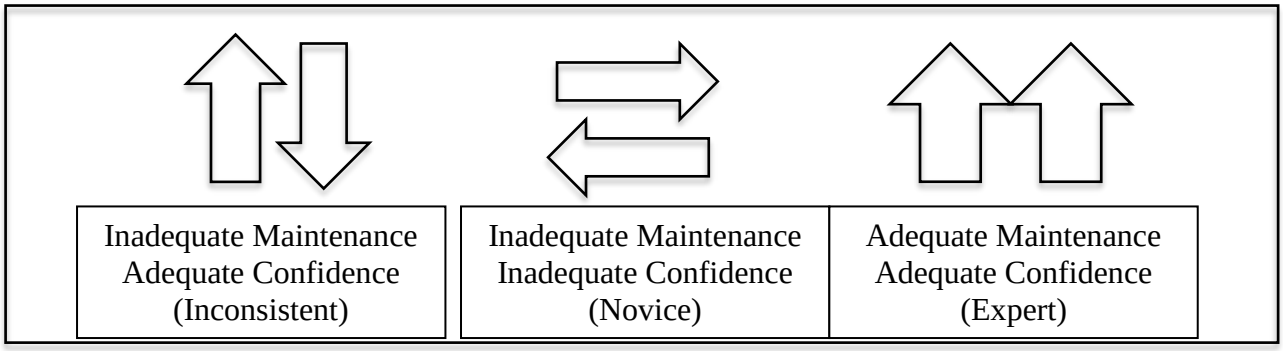


Figure 9: Typologies of Heart Failure as supported by Quadratic Regression

In this sample, those in the novice group were overwhelmingly African American as compared to the novice, expert, and inconsistent groups. There were no notable differences between groups in regards to age, marital status, living arrangements, or education. Because of the higher number of African Americans in the novice group, this may lead to the inference of a cultural component to the relationship between heart failure self-care maintenance and heart failure self-care confidence.

Integrating quantitative and qualitative data allowed the researcher to make valuable connections between a quantitative instrument and qualitative interview data. Quantitatively, participants were scored based on previously determined standards of heart failure self-care (score $\geq$ 70 on the SCHFI). While the SCHFI determines the level of adequacy in heart failure self-care, additional investigation via qualitative methods was needed to further describe how the patient's active or passive role in their heart failure self-care affected their everyday behaviors.

Evaluation of Theoretical Framework

Low self-care maintenance coupled with high self-care confidence may be attributed to a number of factors including heart failure experience and knowledge or discomfort with reporting self-care behaviors or the lack of self-care behaviors. Within the theme of "Denial and Misunderstanding" identified through the qualitative strand of the study, there was evidence on the reliance on past experiences. One participant cited her past medical and career experience as a facilitator of her own self-care. This adoption of past experiences is reflective of an active role in self-care and a cornerstone in the Naturalistic Decision Making (NDM) theory. "I used to be a nurse, you know, so I know the lingo," [87]. Using the concept of NDM and relying on past experiences to make better and more educated health care decisions is reflected in both the

Situation-Specific Theory of Heart Failure Self-Care and through the qualitative responses of women living with the chronic condition.

Previous research supports active and passive roles within the NDM framework (Riegel, Dickson, & Topaz, 2013). The perception of a heart failure symptom and that symptom's management is a fundamental step within the heart failure self-care process (Figure 2). Knowledge from previous experience was evident throughout the qualitative transcripts. One participant recalled her mother's experiences with symptoms when describing her own. "My ankles swell sometimes. My ankles and my feet too….All I know is I, you know, I remember my mother having swelled ankles and swelled feet…her doctor tells her that she has water! I try to reduce the salt in my diet." This participant took an active role in her heart failure self-care through recognizing the symptom after performing her maintenance behavior, perceived it as an exacerbation of heart failure and appropriately managed the symptom by reducing the salt in her diet.

Implications for Nursing Education

This study highlights the unique characteristics of women living with heart failure. There is evidence from the qualitative interviews supporting a need for stronger education as many women stated conflicting ideas regarding their daily heart failure practices. Nurses working with this population should be further educated on the specific needs of women and how heart failure both physiologically and psychologically affects women. In addition, non-Caucasian women may have a separate set of needs that should be individually addressed (Colvin et al., 2015).

The need for enhanced and therapeutic communication should be taught to nurses early and nurses should be encouraged to integrate advanced communication techniques into daily practice. It has been well documented that nurses may not have sufficient knowledge in evidence

based heart failure care and interventions to increase heart failure related knowledge improve patient outcomes (Sterne, Grossman, Migliardi, & Swallow, 2014; Albert, Cohen, Liu, Best, Aspinwall, & Pratt, 2015; Hart, Spiva, & Kimble, 2011). Assessing the home-life and gaining a deeper understanding of what motivates a patient to practice their health-related behaviors may aid in planning more effective heart failure self-care interventions. Heart failure is a common diagnosis among the clients of homecare agencies as much of the heart failure population remains out of the hospital and living in the community. In a cross-sectional survey conducted across four homecare agencies and 94 homecare registered nurses, it was confirmed that there is a need to design heart failure education programs for nurses caring for the community based heart failure population (Delaney, Apostolidis, Lachapelle, & Fortinsky, 2011). Improved education programs for nurses providing care to these patients may lead to greater knowledge and more successful heart failure and heart failure self-care outcomes.

Healthcare providers providing outpatient education and management of heart failure should continue their own education and stay up-to-date on heart failure guidelines and recommendations. It is known that heart failure patients can benefit from a moderate amount of physical activity, yet studies indicate that physical activity is highly variable in this population (Dontje et al., 2014). While some women that participated in this study reflected on the need to frequently rest their heart at the recommendation of their healthcare provider, many women also spoke of the enjoyment they experience while doing physical activity, such as walking.

While designing interventions tailored to improving heart failure self-care, it is important to note the relationship status of the patient. Investigating beyond marital status and further into the role of the caregiver or other means of social support is important. Heart failure self-care

interventions should be designed in a dyadic context and the implications for the patient as well as those close to the patient should be examined (Buck, Kitko, & Hupcey, 2013).

Implications for Nursing Practice

It is important that women living with heart failure have clear and streamlined education regarding their condition and the behaviors necessary to manage symptoms and exacerbations. Many women are managing multiple, complicated co-morbid conditions. Understanding the female patient with heart failure, her home life, her social support, and the factors in her life that contribute to her well-being is an important implication to nursing practice.

Nurses often assume a role as a health promoter and should be highly skilled in planning, implementing and evaluating health promotion interventions, especially with the chronic disease population. The nurse practicing in both acute and community settings should incorporate disease prevention, community orientation, and empowerment of the patient into their practice (Kemppainen, Tossavainen, & Turunen, 2012). Nurses should use and understand various interview techniques that enhance one's self-efficacy to aid in overcoming barriers to self-care. Ensuring patients have ample peer support should also be integrated into a patient's plan of care (Baumann & Thanh, 2012).

Implications for Nursing Research

Research implications in the realm of women and heart failure self-care are numerous and varied. Further well-designed and rigorous nursing research studies specifically focused on a female sample should be conducted to continue the investigation into the unique heart failure self-care needs of women. To date, there are no randomized controlled trials that explore the relationship between self-care confidence and heart failure self-care maintenance. Further

researchers should consider both self-care maintenance scores and self-care confidence scores when planning potential interventions.

As evidenced by the quadratic regression in this study, it may be possible that a high self-care confidence score does not reflect adequate heart failure self-care maintenance behaviors. Therefore, additional studies focused on the women with high self-care confidence and low self-care maintenance should be conducted to better understand the existing knowledge and practice gaps. Further investigations that classify symptoms into clusters are warranted (Herr et al., 2014). Understanding if the patient engages in an active or passive role related to their heart failure self-care will also ensure clinicians are providing the most supportive and individualized interventions. Finally, future studies considering the impact that additional variables such as co-morbid conditions, length of heart failure diagnosis and heart failure health literacy have on heart failure self-care maintenance should be considered.

Implications for Nursing Policy

Heart failure carries an enormous economic burden. Heart failure is the leading cause of hospital re-admissions (Sterne, Grossman, Migliardi, & Swallow, 2014) and cost implications for exceed $1 billion each year. Many of these costs are not reimbursed by agencies such as Medicare and Medicaid (Banoff, 2016). Nurses should consider the financial burden when designing an individualized plan of care for the patient diagnosed with heart failure. Consideration should also be given to the amount of finances lost to caregivers that are unable to work while caring for an individual with heart failure. Institutions and agencies should place importance on developing and adhering to policies regarding reducing readmission rates and evidence-based education modules for those serving this vulnerable population.

Strengths of the Study

A strength of this study lies in its novelty and design. It was the first mixed methods study to focus on heart failure self-care maintenance exclusively. The unique focus on women is also unique to this study. Because heart failure is a complicated diagnosis, collecting data through a quantitative and qualitative lens gives a more comprehensive and complete picture of the entire self-care process. Utilizing both inductive and deductive processes allowed the researcher to analyze data and generate new knowledge from multiple viewpoints.

Patients that were interviewed for this study provided rich and telling descriptions of their day-to-day heart failure behaviors and gave new insights into motivating factors. Patients were not inconvenienced or pressured into participation. Participants had the opportunity to participate either in person or via telephone to enhance their own comfort and convenience. When available, caregivers were invited to participate to generate a complete understanding of the participant's lifestyle. All efforts to maintain patient confidentiality were upheld.

Limitations of the Study

This study was limited by its small sample size and by the use of a convenient sample. A statistically significant correlation between self-care maintenance and self-are confidence was not observed. Participation was limited to one outpatient clinic; therefore, making generalizability to other populations difficult. The majority of participants were African American (68%, n = 21). Although the SCHFI is the most widely used instrument to investigate heart failure self-care, its Cronbach's alpha's in each of its domains of self-care maintenance, management and confidence are less than ideal (0.64, 0.71, 0.77, respectively).

No measure was used to assess baseline cognitive function and participants were trusted to answer the questions on their own accord. There may have been social influence to report

higher levels of education or to appear more compliant to recommended heart failure treatments. The possibility of a social desirability response bias occurs when a participant misrepresents themselves to appear more appealing to the researcher (Polit & Beck, 2017). The primary researcher directly observed two participants that made statements that directly reflected the SCHFI questions.

Conclusion

This study investigated the varying factors that impact heart failure self-care behaviors in women and discovered important vulnerabilities not yet identified in previous studies. It was found that in a population of women living with heart failure, self-care confidence is highest in those that score lowest on the SCFHI and those that score the highest. Those women scoring closer to the median of the distribution of scores seemed to have the lowest self-care confidence scores. Gaining a deeper understanding of the different factors, both positive and negative, that influence a woman's heart failure self-care behaviors was also presented through this study. Ensuring strong social support through family and friends as well as the healthcare provider and providing support to women that encounter dramatic lifestyle changes and co-morbid conditions are important implications. Nurses providing direct care to this population should empower women to take an active role in their heart failure self-care. Finally, incorporating motivating factors into a patient's plan of care may help to improve self-care confidence and thereby, heart failure self-care maintenance behaviors.

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Appendix 1- RN Script for Patient Recruitment

Bridgeport Hospital Clinic Nurse Manager and a Registered Nurse (RN) that is responsible for conducting heart failure (heart failure) teaching will identify potential participants on a biweekly basis (Tuesdays and Thursdays). Patients with heart failure attend the heart failure clinic biweekly on Tuesdays and Thursdays. The manager of the Cardiac Clinic has arranged for the student researcher to have private office space at the clinic on Tuesdays and Thursdays. The clinic RN will explain the purpose of the study and invite women who meet eligibility criteria to participate when they check-in for their appointment. The clinic nurse will use a script prepared by the student researcher to ensure consistency in recruitment procedure (Appendix 1). Patients who verbalize an interest in participating in the study will then be introduced to the student researcher by the clinic nurse or nursing manager. The student researcher will be responsible for further screening the patients for eligibility based on the presented criteria. The student investigator will review the study protocol and informed consent with each potential patient, answer any questions, and invite eligible patients to participate. The investigator will then obtain informed consent from those patients interested in participating in the study. Participants will then be asked to complete the SCHFI before or after their appointment with the physician.

The Clinic Nurse Manager/RN will invite patients with heart failure to participate in the study using the following script:

Script for Bridgeport Hospital Clinic Nurse Manager/ RN:

Purpose of the Research Study

Bridgeport Hospital is participating in a research study with the University of Connecticut to improve outcomes in patients with heart failure. The primary aim of this study is to identify key differences in women who are experts and women who are novices in heart failure self-care maintenance behaviors and how confidence influences these behaviors defined by the Self-Care of Heart Failure Index (SCHFI). You will be asked to complete a short demographics survey and the SCHFI. This should take approximately 15 to 20 minutes of your time. Depending on the score of your SCHFI, you may be asked to participate in a follow up interview. The results will be used to assist in developing interventions to reduce hospital admissions, improve quality of life, and increase patient's self-care practices for women with heart failure.

We would like to invite all women with heart failure who are being treated at the clinic to participate in the study.

Participation is Voluntary

Your participation in this research study is completely voluntary. If there is any time within the study process that you wish to withdraw from this study, you are free to do so. There will not be any consequences at any time if you choose to withdraw from this study.

Study Participation

Participation in this study will involve that you do the following:

A member of the study team will visit you and ask you to complete:

- A demographic questionnaire- (will take about 5 minutes)
- The Self-Care of Heart Failure Index (will take about 15 minutes)

- Depending on the score of the SCHFI, you may be asked to participate in a follow up interview lasting approximately 20-30 minute

Appendix 2: Self-Care of Heart Failure Version 6.2

SELF-CARE OF HEART FAILURE INDEX

All answers are confidential.

Think about how you have been feeling in the last month or since we last spoke as you complete these items.

SECTION A:

Listed below are common instructions given to persons with heart failure. How routinely do you do the following?

	Never or rarely	**Sometimes**	**Frequently**	**Always or daily**
1.Weigh yourself?	1	2	3	4
2.Check your ankles for swelling?	1	2	3	4
3.Try to avoid getting sick (e.g., flu shot, avoid ill people)?	1	2	3	4
4.Do some physical activity?	1	2	3	4
5.Keep doctor or nurse appointments?	1	2	3	4
6.Eat a low salt diet?	1	2	3	4
7.Exercise for 30 minutes?	1	2	3	4
8.Forget to take one of your medicines?	1	2	3	4
9.Ask for low salt items when eating out or visiting others?	1	2	3	4

10. Use a system (pill box, reminders) to help you remember your medicines?	1	2	3	4

SECTION B:

Many patients have symptoms due to their heart failure. Trouble breathing and ankle swelling are common symptoms of heart failure.

In the past month, have you had trouble breathing or ankle swelling? Circle one.

1) No
2) Yes

11. If you had trouble breathing or ankle swelling in the past month… (circle **one** number)

	Have not had these	**I did not recognize it**	**Not Quickly**	**Somewhat Quickly**	**Quickly**	**Very Quickly**
How quickly did you recognize it as a symptom of heart failure?	N/A	0	1	2	3	4

Listed below are remedies that people with heart failure use. If you have trouble breathing or ankle swelling, how likely are you to try one of these remedies? (circle **one** number for each remedy)

	Not Likely	**Somewhat Likely**	**Likely**	**Very Likely**
11. Reduce the salt in your diet	1	2	3	4
12. Reduce your fluid intake	1	2	3	4
13. Take an extra water pill	1	2	3	4
14. Call your doctor or nurse for guidance	1	2	3	4

15. Think of a remedy you tried the last time you had trouble breathing or ankle swelling, (circle **one** number)

	I did not try anything	**Not Sure**	**Somewhat Sure**	**Sure**	**Very Sure**
How sure were you that the remedy helped or did not help?	0	1	2	3	4

SECTION C:

In general, how confident are you that you can:

	Not Confident	**Somewhat Confident**	**Very Confident**	**Extremely Confident**
16. Keep yourself free of heart failure symptoms?	1	2	3	4
17. Follow the treatment advice you have been given?	1	2	3	4
18. Evaluate the importance of your symptoms?	1	2	3	4
19. Recognize changes in your health if they occur?	1	2	3	4
20. Do something that will relieve your symptoms?	1	2	3	4
21. Evaluate how well a remedy works?	1	2	3	4

Appendix 3 – Demographics Questionnaire

Age: _____

Race:

a.) White
b.) African American
c.) Asian
d.) American Indian/ Alaskan Native

Work Status:

a.) Part Time
b.) Full Time
c.) Retired
d.) Unemployed

Marital Status

a.) Married
b.) Divorced
c.) Widowed
d.) Single

Highest Level of Education

a.) Grade School
b.) High School
c.) Bachelor's Degree
d.) Master's Degree
e.) Doctorate

Living Arrangements:

a.) Alone b) With Someone else

Years diagnosed with Heart Failure: _____

Appendix 4: Table of Contents: Figures and Tables

Figures

Figure 1: The Situation Specific Theory of Heart Failure Self-Care Model 4

Figure 2: Diagram of the self-care process 5

Figure 3: Diagram of the Convergent Mixed Methods Design 34

Figure 4: Distribution of Self-Care Maintenance Scores 52

Figure 5: Quadratic Regression Model 56

Figure 6: Display of three groups generated from Quadratic Regression 76

Figure 7: Histogram of years living with heart failure 77

Figure 8: Typologies of Heart Failure Self-Care 87

Figure 9: Typologies of Heart Failure as supported by Quadratic Regression 87

Tables

Table 1: Summary of heart failure self-care mixed methods studies 11

Table 2: Demographic Profile of the Participants 49

Table 3: Demographic Profile: Adequate Vs. Inadequate 51

Table 4: Coefficients for Quadratic Regression 55

Table 5: Statements on heart failure self-care in participants scoring inadequately ($\leq$ 69) 58

Table 6: Statements on heart failure self-care in participants scoring adequately ($\leq$ 69) 58

Table 7: Inadequate scores ($\leq$ 69) Example of Negative Cluster Dendrogram 59